

# **ASSESSMENT OF VISION AND HEARING OF DEAF-BLIND PERSONS**

**LEA HYVÄRINEN  
LINDSAY GIMBLE  
MARTTI SORRI**

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# **ASSESSMENT OF VISION AND HEARING OF DEAF-BLIND PERSONS**

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To the memory of my beloved teacher  
Dr. Frank B. Walsh

# Foreword

SINCE 1981 the Nordic Staff Training Centre for Deaf-Blind Services in Dronninglund, Denmark has arranged courses for all personal categories involved in the care of visually impaired-hearing impaired individuals. In that work we experienced that communication was often the most difficult problem when developing services for this group of people. Although the problem was recognized it was not possible to set aside money and time for studying it until Dr. Arthur Jampolsky suggested that I spend a sabbatical year at Smith-Kettlewell Eye Research Institute, which was made possible by a grant from National Science Foundation through the Academy of Finland.

The manuscript of this book was mostly written during the project at Smith-Kettlewell in 1987-88 as a result of the clinical examination of numerous deaf patients with retinitis pigmentosa, macular degeneration or other less common eye diseases. During these examinations Lindsay Gimble was my interpreter, research assistant, social worker and secretary and afterwards analysed the videotapes with me. Her contribution may not be clearly enough visible in the final product, but without her vast experience in communication and her willingness to try to communicate, even when it seemed to be impossible, this work would never have been completed. The project involved almost everyone at the institute and was always given enthusiastic and skilled support, for which I would like to express my deep gratitude.

When the manuscript was used as study material at a meeting of medical experts at our Nordic Centre, it was suggested that a few chapters be added on audiology so that the book could be used in both specialities involved in services for the deaf-blind individuals. Dr. Martti Sorri has written the chapters on audiologic examination during a project supported by the Academy of Finland.

I would like to express my appreciation to the many hearing impaired-visually impaired persons who have taught me about their problems in communication and about deaf culture. It has been one of the most rewarding experiences in my work as an ophthalmologist and vision researcher. It is my sincere hope that this book will help them in getting the better services they so rightly deserve.

**Lea Hyvärinen**

Helsinki  
October 1989

Motto:

There are few human activities we value more, understand less, and perform worse, than  
person-to-person communication.

(Robert M. Soucie 1979)



# **PART I**

## **Communication During Assessment of Vision of Deaf-Blind Persons**

# Deaf-Blind Patients in Departments of Ophthalmology

THE total number of deaf-blind individuals is relatively small and they are not accustomed to asking for services since they often have no information about the availability of services. It is therefore hardly surprising that many physicians have never met a deaf-blind person. If they have encountered such a patient, the focus of treatment centred on his disease, and not on the patient as a person. Most ophthalmologists and audiologists do not recognize deaf-blindness as a special problem, and this often becomes the greatest problem related to medical services for the deaf-blind population: their hearing is assessed by one group of professionals, their vision by another group and these two groups of specialists usually do not meet to discuss deaf-blindness.

The loss of both distance senses is a specific problem causing unique rehabilitation needs in communication, mobility and activities of daily living (ADL). Therefore there should be at least one, preferably two, professionals in each university eye department and ear, nose and throat (ENT) department or speech and hearing department, well educated in the problems related to deaf-blindness. They will not see deaf-blind patients very often, because in the great majority of cases the progression of the disease is very slow and the need for reassessment is rare.

During vision assessment of deaf-blind patients the following tests are employed:

1. traditional clinical tests
2. clinical tests modified to facilitate communication
3. complex test situations in clinical or experimental laboratories.

In general, most of the tests that are used in the visual assessment of the normally hearing visually impaired are applicable to the examination of deaf persons, too. The selection of tests varies in individual cases, depending on the disease, the degree of visual impairment, and the language level.

The assessment usually has two goals: a further clarification of the clinical diagnosis of the eye disorder, and an in-depth analysis of the type of vision loss for rehabilitation purposes.

Basically we have to assess the following functions:

1. Oculomotor functions, including accommodation
2. Visual field
3. Visual acuity
4. Contrast sensitivity
5. Color vision
6. Adaptation.

We should also assess the quality of motion perception and rod-cone interaction in all diseases that may cause abnormal perception because of diffuse retinal lesions. Unfortunately there are no routine tests available yet for this purpose.

Before visual assessment of visually impaired, deaf or hard of hearing persons can be executed properly, both the ophthalmologist and the interpreter have to learn how to communicate in this rare situation where vision is being used for communication at the same time as it is being assessed.

Chapters XI to XXIV are written for eye doctors and interpreters. They describe the most common problems related to assessment of vision and offer suggestions on how to solve these problems. The videotape\* that accompanies this book demonstrates some frequently encountered difficulties in interpretation of ophthalmological terms and expressions as well

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\* Lea Hyvärinen, Daniel Veltri, Lindsay Gimble, Communication During Visual Assessment of Deaf-Blind Persons. Video available from Daniel Veltri, 38 Ord Street, San Francisco, CA 94114, USA.

as adjustments necessitated by the visual impairment of the patient.

The third subject in the assessment, the patient, needs additional new information as well. For them there will be a book on "Eyes and Vision", to be published in Canada, and a videotape covering most of the information in the book. By educating all three persons involved in the assessment of vision we may get better results in the future.

## General Expectations During Communication

ALTHOUGH we nowadays are in contact with numerous cultural minorities, the ability to understand and cope with different languages and cultures is not required of medical professionals even in centres serving patients from all over the world. It is no wonder, then, that the understanding of deaf culture and sign language has been quite limited until recently. As an introduction to deaf cultures and sign languages, it may be worthwhile to first analyze our patterns of communication from a more general perspective.

We are sensitive to facial expressions, and often react negatively to deviant expressions. For example, individuals with cerebral palsy are often misinterpreted because of their grimaces. Patients with bilateral facial palsy are often experienced as nonchalant or cold because of their lack of expressions. This is particularly likely to happen if the patient is totally deaf and we lose information conveyed by the tone of voice which cannot be controlled accurately.

Facial expressions of deaf people differ from those of hearing persons and are sometimes

experienced as disturbing — not to the point of preventing the information from being transmitted but disturbing enough so that the doctor's reaction is altered at times causing some rejection.

In everyday communication among hearing people, we expect certain listening actions. Among the white, western population it usually means rather frequent eye contact and attentive behavior from the listener (those colleagues who see patients with other cultural backgrounds should be aware that listening actions are different in many cultures). We expect to see some active listening responses at certain moments of communication to be sure that the person understands the information given. This is interactional listening. Because of the time lag in communication when interpretation is used, the listening action becomes "out of synch". When signed information is used, not only is there a time lag but the attention of the patient is directed to the interpreter.

Fixed attention from the patient, before attempting explanation, is something we are all accustomed to. This crucial interaction is often disturbed in cases of visual impairment since the patient does not seem to fixate on the face of the speaker due to extrafoveal viewing or nystagmus. Deaf patients often show usual fixed attention briefly when the doctor begins to say something. They first try to get a visual clue about the attitudes of the doctor and then turn their attention away from the doctor to the interpreter who has to delay the signing until the patient has established contact.

Doctors usually learn to suppress the negative feelings and uncertainty (insecurity) related to abnormal eye contact. The lack of normal eye contact may disturb the interpreter's work. We have to remember to explain to the interpreter how the patient is using his vision if he seems not to be looking at the interpreter. This is always a delicate situation because we often forget that our communication is to the patient and not to the interpreter. It is important to remember to start by saying "You know that you use the side part of your vision when you look at something. I must explain it to the inter-

preter'' . . . then explain. The interpreter will then translate your discussion to the patient as a discussion between you and the interpreter.

Since the deaf person is primarily looking at the interpreter and not the doctor, the doctor may experience the interpreter as a rival in his own office. If one accepts the role of the interpreter as "a talking machine", one is less likely to see him as a rival or as a person responsible for things other than interpretation.

Total communication is a term that describes the communication used by deaf persons. It is not just sign language, but a rich mixture of signs, expressions, mime and body movements used to convey the message, often much more expressive than our academic English. Since we tend to assume that deviations, even rather minor deviations in bodily expression, are indicative of deviations in personality structure, we may be confused by the body language related to deafness. Very few physicians or nurses have experience in deaf culture and therefore the "deviant" body language is often erroneously attributed to aggressive behavior when the contrary is true. This misunderstanding can be dangerous. It has happened more than once that psychologically healthy, deaf patients have been taken into closed psychiatric wards when they have become upset, cried and signed passionately in a doctor's office, frightening the inexperienced staff working without an interpreter.

When a deaf person develops visual impairment, or a visually impaired person loses hearing, communication is bound to become problematic. This is true in medical examinations as well. The loss of reliable communication in both major channels, combined with seemingly negative feedback from the patient, may create a tense atmosphere which many deaf patients and their families describe as "very unpleasant, to say the least".

An additional negative factor is related to the fear of the dual sensory disability, and to the misbelief that deaf-blind individuals are unable to function on almost any level, a misbelief still quite common among both ENT and eye specialists everywhere. A specialist who is

afraid of deaf-blindness conveys that fear through his body language which the patient often understands better than the spoken information sprinkled with Greek and Latin terms. In this case the visit, instead of being a part of the patient's rehabilitation, becomes an additional emotional blow and burden.

We should learn from the recent publicity on deafness and deaf education that numerous deaf and deaf-blind individuals work at many skilled and demanding occupations. They may be college or university professors, writers, poets, mathematicians, engineers, psychologists, public relations specialists, graphic designers, actors, librarians, counsellors and accountants, as well as engaging in the numerous traditional jobs of blind craftsmanship. The dual sensory impairment does not need to be the limiting factor for schooling and occupation today.

If we learn to analyze our own expectations and those of the patient, and remember that when communicating with deaf-blind persons some of our usual expectations are unrealistic, the entire situation becomes a lot easier.

## **Some Facts about Sign Language and Interpreting**

THIS short description of sign language and interpreting is written by an ophthalmologist for my colleagues in order to keep the language devoid of the many fine expressions that linguists are apt to use. My knowledge of American Sign Language (ASL) is minimal, but I have had exposure to sign languages and deaf culture in other countries.

Sign language may seem to be a haphazard



collection of gestures when looked upon by a person who does not see the minute differences in the movements of hands and fingers, and who does not understand the spatial and visual structure of signed information.

A rather common misconception about sign language is that it is visualized English. American Sign Language (ASL), the mother tongue of deaf communication, is a distinctly different language. There are also different ways of presenting English manually, either by fingerspelling (visual handshapes of the manual alphabet, Figures 1 and 2) or by Signing Exact English (SEE). There is also Pidgin Signed English (PSE) which uses signs but is closer to English than ASL in its syntax. Sometimes we see families that use homemade signs and gestures that do not fulfill the definition of any formal sign language.

The existence of several different forms of manual communications means that we must remember to ask the patient what type of sign language should be used during the interpretation, or which interpreter the patient would prefer in medical communication.

In our work as physicians we need to know that sign language is far more logical and structured than our spoken language. When a new concept, person, object, is mentioned for the first time, it is described and “placed” in a certain location in the visual space. When the concept is referred to later, it is pointed to in the signing space. It does not need to be defined each time it is used.

The use of a specific location in space to specify a person or function makes signed information often very quick and therefore hard to translate into speech or *to voice* (reverse



Figure 1A. One-handed manual alphabet. Pocket-size copies of the manual alphabet card are available. (Finnish)



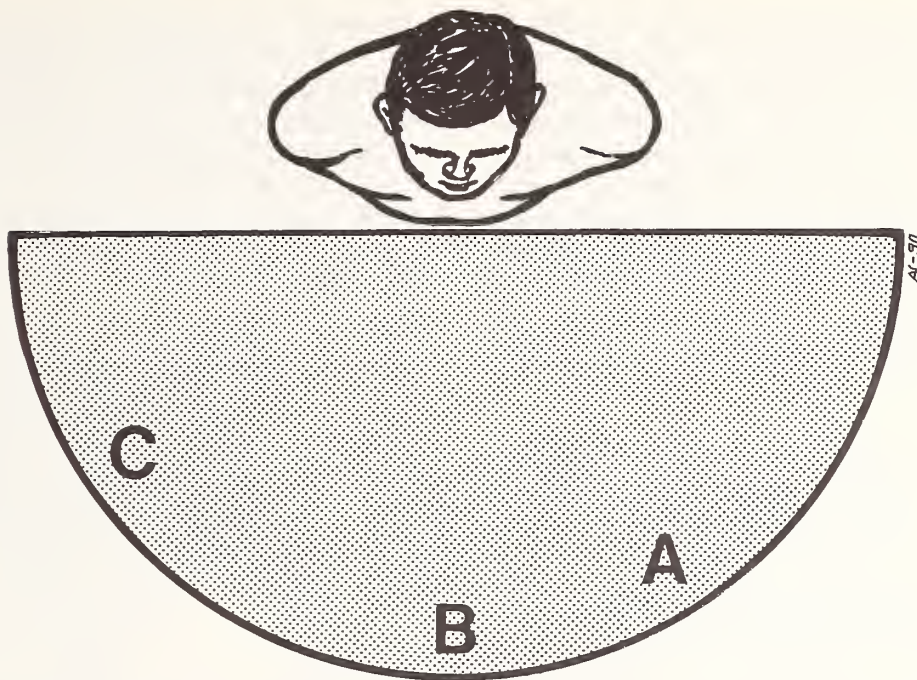
**LEFT HANDERS SHOULD REVERSE ALL FORMATIONS.**

*Figure 1B. Two-handed manual alphabet. (Australian)*

interpretation). For example, the left hand of the signer may be used to speak for the signer himself and the right hand for another person. It then becomes possible for the signer to describe an argument between these two persons with one hand saying "yes" and the other hand almost simultaneously saying "no"! Another example of effectiveness of signed information is when the patient signs with two small movements "bilateral cataract extraction with lens implants", the first small vertical

movement in front of both eyes depicting the surgery and the other movement depicting how the implant is put in place. On the other hand, there are numerous situations where the interpreter has to sign for quite some time to cover something that can be expressed by just a few spoken words.

Quite often the interpreter has to ask the patient to slow down or pause in order to catch up with the tidal wave of signed information. Similarly, the doctor may sometimes be asked



*Figure 2. The patient describes three persons and defines their locations to be used during that part of the conversation. Later, the verb signs move from the location of the "doer" to the location of the person who is the object of the action.*

to wait for a while so that the interpreter can catch up. We have to learn to accept the interpreter as the communications supervisor.

Interpretation from spoken language into sign language and vice versa can be either simultaneous or consecutive. In medical examinations it is most often consecutive until the doctor and the interpreter have worked together sufficiently long that the examination situation and the phrases used are mastered by both persons.

Due to the fact that deaf people pay particular attention to the detailed description of each person or object to be discussed, we should learn to define each new subject carefully and make sure that the patient knows what we are talking about. If the concept is new and there is no commonly used sign for that concept, it first has to be fingerspelled and then clarified, using signs. This is the responsibility of the interpreter, but the doctor has to be aware of the need for extra time and has to wait patiently

until the end of the signed message. In some cases, the interpreter may need to ask the doctor for help in formulating the clarification.

Another typical feature of sign language is the use of actual, sequential time order in describing a series of events. In ASL the focal point of the comment goes at the end of a statement, rather than at the beginning as is common in English. For example, in spoken language we can say "Does your visual field get smaller when you enter a dimly-lit room?". In sign language the event that happens first is signed first. Thus, in ASL the statement would be "When you enter a dimly-lit room, does your visual field get smaller?". If we can remember this simple example we will make the interpreter's work a lot easier, since the interpreter cannot start the sentence before the doctor has described the event that happens first.

The speed at which a patient can easily perceive signing is related to both his compe-



tence in sign language as well as the nature of his visual impairment. Our current tests used in assessment of impaired vision do not reveal the degree of loss of temporal resolution, changes in motion perception, or the perception of exact positions of fingers and arms which probably are quite important in the communication of deaf persons. Since we cannot measure the degree of communication impairment, we have to carefully ask the patient whether signing with normal gestures is acceptable and use that information in our reports.

Although sign language is visual, it is not visual in the word's usual meaning. Our visually impaired patients whose visual fields are limited to a few degrees perform their signing in a space that does not visually exist for them. When we try to sign with smaller signs to make them fit in the small tubular field of new patients, these persons often dislike it and would rather sit at an unusually long communication distance, in order to retain more ordinary signing. This might be related to the fact that signs have well-known relationships with different body parts. If removed from its normal location in space the sign also becomes detached in its meaning. When a deaf-blind person with a small tubular field comes in contact with other similarly affected deaf persons, the use of smaller signs is often accepted rapidly.

Lipreading is often thought to be an essential part of sign language and deaf people are often expected to be able to lipread so well that they can use it as their sole means of communication. The ability to lipread is very individual, and it is never a hundred per cent correct when uncommon vocabulary, such as medical terminology, is used.

Any new language that we learn means exposure to a new culture since language and culture are intimately interrelated. Therefore we have to be prepared to deal with cultural and attitudinal differences, too. There are a few things that many deaf persons experience as insulting, more so than hearing persons can imagine. One common mistake is to assume that the patient has the ability to lipread and

to want to measure it as a part of the assessment of visual functioning. Lipreading tests should be introduced only if the deaf person uses lipreading in communication. Another insulting request is to ask a deaf person who uses ASL to talk. This seems to occur in medical institutions even in situations where there is no need for the patient to talk since there is an interpreter present. The request for speech makes no sense and only serves to alienate the patient from the medical specialists.

Among the many publications related to sign language the research report "Language Research: New Views of How the Brain Works" from the Salk Institute for Biological Studies, P.O. Box 85800, San Diego, California 92138 is particularly relevant to an ophthalmologist.

## Different Types of Communication used by Deaf-Blind Patients

ALTHOUGH the total number of deaf-blind patients is small, the number of different communication systems used by them is surprisingly large. This is naturally related to the many different types and degrees of deaf-blindness. If we consider the *time of onset of the impairments* we get nine different categories of deaf-blindness:

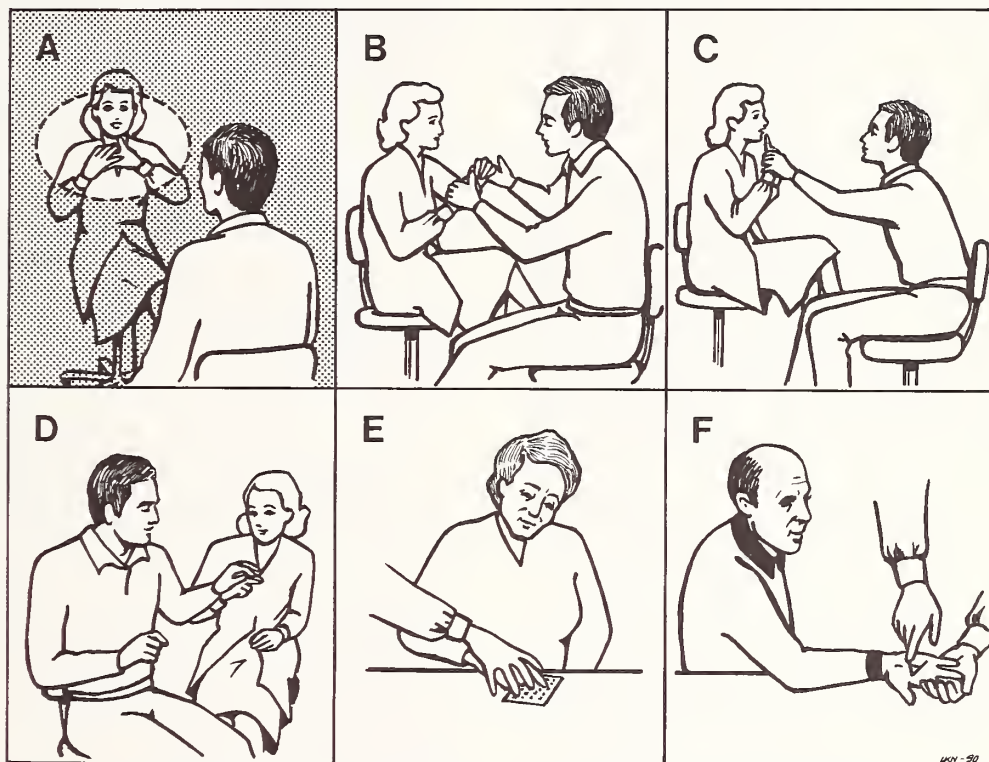
1. born deaf:
  - blind from birth
  - visually impaired with some useful vision in childhood
  - visually normal or nearly normal as a child, impaired later



2. born hard-of-hearing:
  - blind from birth
  - visually impaired with useful vision as a child
  - visually normal as a child, impaired later
3. born with normal hearing, hearing loss later:
  - blind from birth
  - visually impaired with useful vision as a child

- normal sight as a child, both impairments later.

Each of these combinations has a different effect on language and cognitive development. Therefore, when dealing with a deaf-blind person we should be aware of the time of onset of both impairments. We should also have information on the early habilitation and language development of the child. In the case



*Figure 3. A. Visual sign language modified to use smaller than normal signs at greater than normal distance in order to place the signs within the limited field of the patient. B. Tactile signing means regular sign language that the blind person perceives tactually. In the beginning it is two-handed and therefore cumbersome in an examination because the interpreter has to face the patient during communication. Later it becomes one-handed and does not interfere with examination. C. The combination of visual and tactile information is called tracking. The person observes the hand of the interpreter tactually while watching the hand movements also visually. D. The one-hand manual alphabet looks to an uninformed observer almost the same as one-handed signing, but the information is fingerspelled tactually on the palm of the patient. E. The braille alphabet card can be used by anyone if the patient knows braille. This card should be available in all emergency units to facilitate communication with a blind braille user who cannot hear well enough with his hearing aid or who may have lost it in an accident. F. Block printing, the writing of regular capital letters on the palm or forearm of the person, is always available. It takes time but is very effective in emergency situations because the physical contact with the signer reassures the patient.*

of deaf children, the very early months of language development are crucial for spoken language and speech. The later the loss of social hearing occurs, the better possibilities there are for intelligible speech. In addition, the type of communication used during pre-school and school years affects communication greatly if a deaf person later loses most of his visual field.

Although the oral method of teaching was perceived as a punishment by many children in the 1930s, those who learned to lipread well and now suffer from visual impairment are much better off with their 4-5 degree visual field at 45-50 years of age than are similarly impaired persons who never learned to lipread. This is not to say that I would recommend forced lipreading for deaf children at the expense of teaching sign language. What I am saying, however, is that deaf or hard-of-hearing children with retinitis pigmentosa should get more training in lipreading than visually normal deaf children because their ability to communicate later in life will be greatly improved. It is generally much easier to learn lipreading as a child, although not all children have that ability.

Deaf-blindness is often related to additional impairments that complicate communication and the acquisition of language. If the additional neurological impairment develops later, it may make expressive or receptive language unusual and difficult to understand. The deaf-blind patient may also have motor impairments that affect the production of speech or signs, even though the understanding of language may be normal. Some patients function below age-appropriate cognitive levels because of sensory deprivation or because of brain damage.

In terms of language, basically we have two large groups of deaf-blind individuals: those who have normal language level (in ASL or English) and those who have limited language. When examining the first group of patients we use techniques used during routine visual assessment, although we must pay extra attention to the physical difficulties of communicating. When examining persons with limited communication we have to rephrase our questions, limit them to a minimum, and rely often on

methods that we usually use in the examination of infants and young children.

Deaf-blind individuals with normal language level (in ASL or English) use more than half a dozen different modes of communication.

#### A. Techniques based on ASL:

1. visual sign language modified to fit the visual impairment
2. tactile sign language.

#### B. Techniques based on written language:

3. tactile manual alphabet, in the United States one-handed (more rare are the alphabet glove, the British two-handed alphabet, and the Central-European Lorm alphabet)
4. braille, either by using a braille alphabet card, printing on the palm, or via Tellatouch, VersaBraille, Dialogos, or Dotless Braille
5. block printing of capital letters on the palm
6. morse code
7. written information, normal or large print, sometimes via CCTV, Viewscan or by using different techniques to enlarge the text on the computer screen
8. Dexter, mechanical fingerspelling hand — a prototype
9. Glove with sensors that convert fingerspelling to text on a computer or to synthetic speech — a prototype.

#### C. Tadoma method, tactile reading of movements of lips and larynx.

Visual and tactile sign language are used by persons who learned sign language as their mother tongue. Some visually impaired patients who lose hearing in adulthood become fluent enough with signs to communicate with deaf persons. When communicating with hearing persons, these late onset deaf persons can use the quite good speech they usually have retained.

The manual alphabet is most frequently used by persons who are born deaf or hard-of-hearing. The use of fingerspelling varies in different deaf populations. Many older deaf persons use fingerspelling more than is

customary in younger ASL users. Reception of fingerspelled information is difficult visually and it is still harder tactually. There are different techniques in receiving the manual alphabet. If a person experiences more than normal difficulty in learning to receive the manual alphabet, different hand positions should be suggested in order to try out different haptic constellations.

Since it is difficult to learn to read braille as an adult, only a limited number of deaf-blind persons use braille information. It is common among persons who lost their sight early and also learned braille early. Braille information requires good language skills and good tactile sensation in the fingertips. The numerous contractions of words are often problematic to anyone who has learned English as a second language.

Dotless Braille refers to a new device which uses a keyboard resembling a regular braille writer. However, the keys are also used for reception and pop up in the usual letter configurations when the keyboard is used for receiving messages.

Block printing should be remembered as a method of communication in emergency situations such as when a deaf person, who has previously lost central vision in one eye, develops macular haemorrhage in the good eye. The person cannot perceive signed information and cannot read instructions except, perhaps, on a CCTV. Most often the patient can calm down and receive information if it is slowly printed on the palm of the hand. It must be remembered that the sentences have to be short and the vocabulary limited to the most common words, since there is no available information on the patient's language level.

Hard-of-hearing patients who have lost their hearing aids are a special problem. Block letters printed on the patient's palm can also be used in this situation. Another often forgotten technique is amplification using a cylinder made out

of the glossy cover of a journal. Roll a journal to a diameter of about two inches and place it against the patient's ear. Speak slowly and clearly, using a lower than usual pitch and you will be surprised to see how well many "deaf" patients can hear.

Written information should be used sparingly when dealing with ASL users and it should be written at the language level of the patient. Written information is, however, important as a part of drawings to clarify diagnostic procedures, anatomical structures, new concepts, etc. Since written information is slow, it is not acceptable as a sole communication method if the patient can use a more fluent type of communication. Communication cards for frequently used sentences, questions and instructions should be available in emergency situations when we have to be able to communicate with the patient before the interpreter arrives.

When I meet with a deaf-blind patient with limited communication for the first time I asked the following "do-we-know" questions about communication and learning. Do we know:

- when the hearing impairment started affecting the two functions
- what was done in early habilitation (if pertinent to the case)
- how communication developed during school age
- what other neurologic deficits may affect communication
- what is the language level (ASL and/or English) of the patient
- who defined it and when
- whether we have missed some crucial information about the past or present situation
- how much variation there is in the level of communication with different persons
- whether there has been a recent change in either hearing or vision resulting in a period of readjustment and learning, e.g. a transition from visual to tactile sign language?



# Ethics of Interpreting

IN Part II of this book the ethics of interpreting are discussed in detail in several instances where the role of the interpreter is in danger of becoming something other than that described in the code of ethics. In order not to place the interpreter in conflicting situations, we must know some basic facts about the interpreter's role.

An interpreter is supposed to translate everything spoken in the room, if that is possible, so that the deaf person has the same information as the hearing persons present. Quite often this is not possible, especially when interpreting tactually. In this case the interpreter has to condense the information and often has to ask people to speak more slowly and only one at a time.

Since the interpreter's first obligation is to make sure that spoken information is truthfully conveyed into sign language, you could not upset the situation worse than by saying "You do not need to translate this to the patient, I'd just like you to know . . ." In a situation like this the interpreter will sign your words just as you said them and will have to correct you, which is not very easy when dealing with a doctor in his or her own office!

In some situations it is advisable to delay the interpretation for a short time while you describe the finding to the interpreter in detail to help him understand the contents exactly. In order not to insult your deaf patient, you should start by saying "I have to talk to your interpreter for a short while to make sure that we understand each other. Please wait a moment, then he will interpret the information to you." Most deaf patients seem to tolerate almost anything, as do our hearing patients, from their doctor but this is no justification for the continuation of any bad habits.

Quite often we need a little help during the assessment. If the nurse is not present it may seem to be natural to ask the interpreter to lend

that help. In principle, only if the interpreter is a member of the hospital personnel with other assigned duties can he be asked to do anything else but interpret. Of course, there is some space for the use of common sense. The situation is quite different if the interpreter is trained to function as a member of the assessment team, but even then we should not hinder interpretation with other duties. Many interpreters experience a medical interpretation as being so demanding that they have to concentrate and use all of their imagination to make the constant jumps from spoken medical English into the world of signs, keeping in mind the restrictions related to the patient's visual impairment.

Uninterrupted interpretation should not last for more than 20 minutes. Since the medical examination has natural pauses, an assessment session of up to two hours can usually be handled by one interpreter. The patient usually needs a break after about 45 minutes and thus the interpreter also gets a chance to rest at these times.

The deaf-blind community is small and therefore the interpreters learn to know most deaf-blind clients quite well. They often have a much more complete picture of the patient's life than the ophthalmologist ever can get. Knowing this, the ophthalmologist may want to discuss the patient's life situation with the interpreter, but that is not proper. The interpreter cannot express opinions on anything else but language and communication. Confidentiality related to everything expressed during an interpreting assignment is as strict as the confidentiality in medical services.

## Planning for the Examination

THE visit of a deaf patient in any medical office requires some extra planning to make

sure that the quality of the examination is the same as that of hearing patients.

If the visit is the first visit in that particular office and if the referring doctor does not give information on the type and level of communication used in previous examinations, it is advisable to confirm the appointment via TDD (telecommunication device for the deaf). In this way we can learn the level of English mastered by the patient so that we know whether to send a questionnaire to be filled out at home, and can ask the patient what kind of communication he or she prefers to use. If the office does not have a TDD, it is possible to use a relay service to get the same information.

Except for the rare cases in which patients say that their lipreading (speechreading) and English are fluent, it is necessary to have an experienced interpreter present during the vision examination. Until now, the patient has usually arranged for interpreters by himself. Patients usually come to know local interpreters well and make appropriate choices for their medical examinations. However, it is better if the hospital trains a few interpreters to function in collaboration with its physicians and other personnel in order to improve the quality of communication.

If the hospital or clinic has no previous experience with interpreter services, the local interpreter referral service can help find interpreters who might be interested in receiving specialized training in medical interpreting. In smaller communities where there are no referral services, a registry of interpreters for the deaf can give the names of interpreters available in a given area. These organizations also give information on which interpreters are certified and thus are likely to be able to perform well as medical interpreters. An effective way of identifying good interpreters is to be in contact with the local deaf community grapevine.

Since taking a case history is time-consuming, as much information as possible should be collected beforehand. This includes gathering copies of old medical documents and the use of questionnaires sent to the patient's home or answered at the hospital before the

examination. However, we must remember that English may be very difficult for many deaf patients and, while some questions are answered correctly, many will be misunderstood. All questionnaires should recommend the use of an interpreter, if needed, when answering the questions. In the future it might be possible to have video materials covering most of the basic questions related to the medical examinations.

The use of questionnaires imposes a new problem. Some patients will be able to respond to written questionnaires without the help of an interpreter in the usual waiting area. However, for those patients who require an interpreter, the waiting room is not an appropriate place to gather information. Signed information is visible at a distance and therefore the privacy of the patient is violated. A screen may be sufficient to solve this problem if a separate room is not available.

Even if the patient and the interpreter have discussed most of the questions before the examination, more time is needed than when examining a hearing patient because the interpretation requires extra time. Guiding the patient from one place to another may take more time, and in all new cases we have to be prepared for a variety of communication problems. When we learn to know each deaf-blind patient better, the time needed for an appointment can be individually planned.

When I see a deaf-blind patient for the first time, I set aside 1 to 1½ hours. For patients who have recently been found in an institution and whose communication is not at all known, we may plan to use one whole morning. In this way I can spend some time with the patient, interpreter and rehabilitation counsellor, and then leave them to discover the best mode of communicating with the patient. Later, I can return to help analyze the observations, and then repeat this process several times. Sometimes we use this same technique with patients whose understanding of concepts related to eyes and visual impairment is very limited, so that there is need for special education before we can discuss the patient's problem. Thus, one

single visit may take as many as four hours, although only a part of that time is spent with the patient.

In order to get copies of old charts we need a consent form from the patient. Usually, this consent form is reasonably easy to understand. When a patient comes to the hospital or to a private clinic and we need consent for any special examination or procedure, enough time has to be allocated for the interpretation and discussion of the contents of the consent form. Otherwise it cannot be considered an informed consent. In some cases it has taken as many as five visits to my office before a deaf patient has been able to sign a consent form for a cataract extraction. It can require all of these visits before the patient understands the nature of the operation and the different options available. We can seldom give written information as homework because written language does not convey enough information to the patient. Often an experienced nurse, working together with the interpreter, can save much of the doctor's time.

Some may ask why not make the decision for the patient if the physician knows that the patient will benefit from a certain procedure, such as a cataract extraction. This is a philosophical question, important in the care of all patients with communication handicaps. Only if the patient is unable to understand the nature of the procedure because of a mental handicap does the physician have the right to make the decision, after consultation with the legal guardian. However, if the patient does not have the mental capacity needed for full understanding, we are dealing with a learning situation and are obliged to teach and inform the patient so that he can make the decision himself.

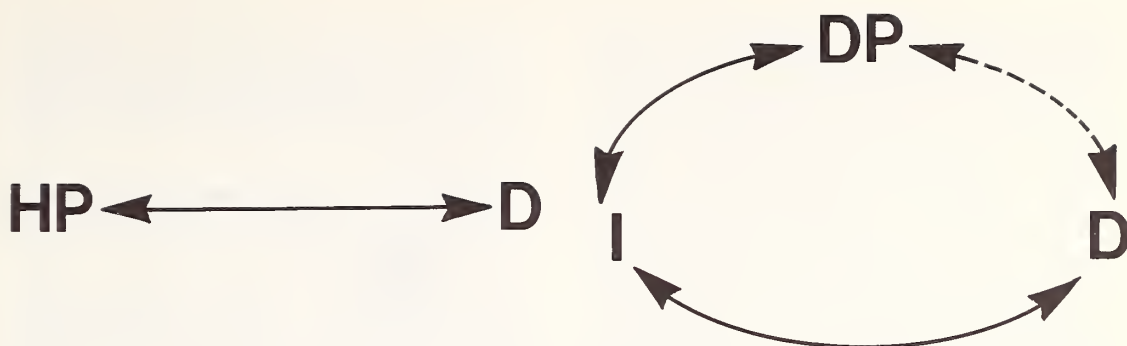
## Interpreting During the Medical Examination

THE use of an interpreter during the medical examination causes problems because of the very technical nature of the vocabulary used by doctors. The interpreter may be fluent in many areas of communication and yet have considerable difficulty in trying to carefully convey the medical information from one language into another. The difficulties of translation from one spoken language into another spoken language are well known and appreciated, whereas the difficulties related to interpretation from spoken language into sign language, and vice versa, are much less well known. A patient may be familiar with the meaning of a medical idiom in his mother tongue, the sign language, but may be lost if the corresponding idiom is "translated", word for word.

Because of the misconception that sign languages are visually presented, simplified spoken languages, the translation is often thought to happen without the usual problems of interpretation. Translation between spoken language and sign language requires the same special skills needed for translation from one spoken language into another. Not everyone who knows sign language can function as an interpreter.

In any communication situation that involves an interpreter there are several different types of communication going on simultaneously. This is depicted in Figure 1.B where the major part of the communication is transferred by the interpreter but a significant part happens directly between the patient and the doctor through body language and facial expressions (dashed line). This direct communication helps the doctor sense how far the interpreter has





*Figure 4. A. Communication between a hearing patient and his doctor is direct and can continue during the different tests. B. Communication between a deaf patient and his doctor is mostly conveyed by the interpreter (solid line). Some of the communication is direct (dashed line) but even this is interrupted during the measurements.*

come in signing and how well the patient may understand the information.

In many tests, communication through an interpreter is slower than spoken communication because it is interrupted each time the patient looks at the test. The test instructions must be explained before the test begins and the test may be interrupted again if the patient does not seem to have fully understood the explanation. The interpreter must usually wait for a moment in order to get an idea of what the doctor is going to ask next, and therefore the interpretation is not simultaneous but slightly delayed. The delay in interpretation decreases when the doctor learns some basic rules of sign language and the interpreter becomes familiar in working with the doctor.

Sign language is very rich in expressions but not in specific signs for a number of concepts that we use during the assessment of health and diseases. These concepts must each be introduced and often explained, all of which requires additional time. If the interpreter knows the patient and his linguistic capabilities and knows the contents of the examination and phrases used by the doctor, interpretation is considerably facilitated, since the interpreter can prepare different ways of expressing certain questions that otherwise would not be understood by the patient. The more often the interpreter and the doctor work together the more they learn about the difficult moments in their

communication, and thus the less frequent these moments become.

The use of an interpreter should never become a barrier between the patient and the doctor. Even if the information goes via the interpreter, the doctor must always address the patient and not the interpreter. It is inappropriate to say "Tell him . . .". The discussion with the deaf patient should have the same character as that with a hearing patient, even if it is slower. During the discussion it often happens that the patient looks at the doctor when the doctor begins to speak or keeps looking at the test when additional instructions should be given. Since the patient is usually out of reach of the interpreter and within reach of the doctor it is the doctor's responsibility to guide the patient's attention to the interpreter, especially in cases when the patient's small visual field makes it impossible for the interpreter to catch the patient's attention.

Although interpreters are asked to function as totally impartial connecting cables between the deaf person and the doctor, they share the emotional stress of patients. If the doctor is rude or nonchalant, the interpreter has to convey the attitude even if it is apparent that this will hurt the patient. By learning to appreciate the work of interpreters, we may learn to express ourselves more gently.

A visit to the ophthalmologist's office is often more stressing than other health visits.

Deaf persons value their sight even more than hearing people do and blindness is often seen as being worse than death. Therefore, a visit to an ophthalmologist, especially when vision is impaired, may be emotionally difficult. The patient's attention may be affected by worries and he may be very sensitive to the way the communication is handled. A person's adjustment to the loss of previous visual capabilities is strongly affected by the attitude of his ophthalmologist. Rehabilitation starts, or is affected negatively, in the office of the first doctor who tells the patient about the impending visual impairment, and it continues to be affected by every subsequent contact.

## Relay Interpreting Using an Intermediary Person

THE term relay interpreting is used when more than one "interpreter" is needed to convey the message. This technique is used whenever the patient does not understand interpreting or the interpreter has difficulty understanding the voice or the signing of the patient.

The reasons for using relay interpreting might be:

- the patient has lost vision recently, can no longer rely on visual sign language and is uncomfortable with tactile sign language but understands a relative or friend
- the patient has a neurological condition that makes the sign language or speech deviate from normal
- the patient needs the support or presence of a family member who may be involved in part of the interpreting although some of the interpreting usually goes directly via the interpreter
- a patient with minimal language skills (MLS) who needs an interpreter who knows his limited vocabulary.

Usually the second person helping in the communication is either a family member, teacher or social worker. However, even if they use sign language they should not function as the only interpreter because it is not humanly possible for such a person to be impartial in the examination process. They usually function as advocates which is a different role than that of an interpreter. Also, we cannot expect that they know how to interpret our medical terminology well enough to cover all of the questions and/or to function properly in the different test situations.

When relay interpreting is used, the time for communication increases as does the possibility of losing some information on the way. Both the interpreter and the physician have to be very alert and sensitive and help the relay person rephrase questions using simple, more common concepts if the patient does not seem to understand. Since we have to use the simplification method, it is important that we ourselves get practice in simplifying the contents of our different questions without losing the exactness of their meaning.

The use of a relay person is one of the most delicate situations in communication. The person is unlikely to know the ethics of interpreting and, even if these rules are known, cannot apply them in communication when there are close, personal ties. We have to accept the fact that the relay interpreter sometimes talks for and instead of the patient. In this case we have to try to rephrase the question, gently suggesting that the question in its new form might be "easier for the patient to understand and answer". We use the relay person as our communication cable and we do not want to break the communication by disturbing the person who is having a hard time without any



additional critical comments on his performance.

In situations where the relay interpreter is deaf and the answers have to be voiced, it is

helpful if the interpreter says who is speaking because the doctor usually has to watch the reactions of the patient and cannot keep track of how much the patient is signing.

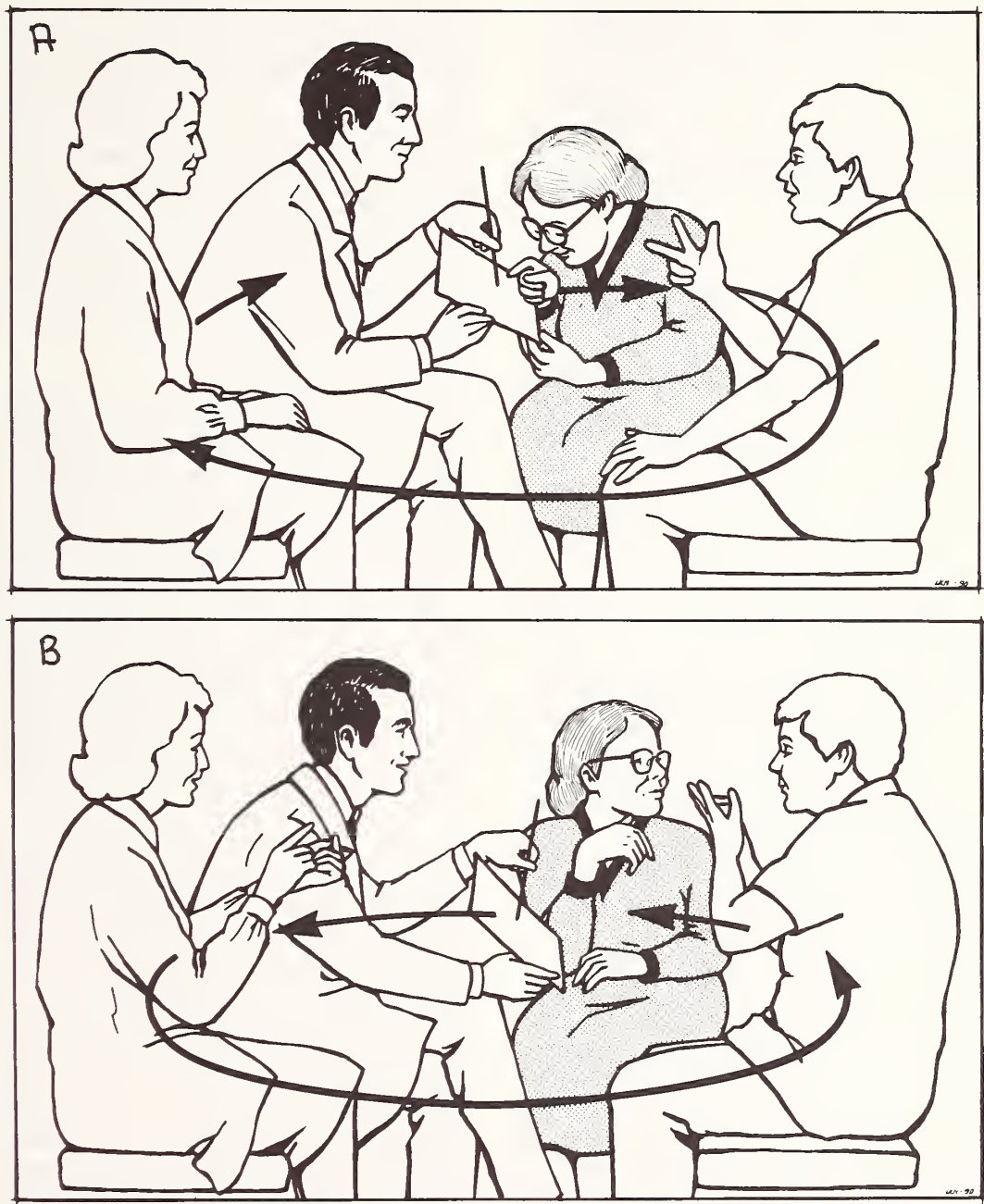


Figure 5. Relay interpreting. A. The interpreter voices the signing of a deaf person who can read the signs of the deaf patient. B. The deaf relay person signs the information signed by the interpreter.

# Adult Patients with Minimal Language Skills and/or Multiple Impairments

PATIENTS with either minimal language skills and/or multiple impairments require an interpreter who has experience in this rare type of medical interpretation. These patients also require that the ophthalmologist has more than the usual experience in language development, communication techniques and clinical neuropsychology in order to be able to recognize or at least suspect that the problem is:

1. a technical problem related to the dual sensory impairment (especially visual impairment)
2. a combination of the sensory impairment and minimal language skills
3. a combination of dual sensory impairment and neurological problems affecting either receptive or expressive communication but with normal language comprehension
4. a combination of dual sensory impairment and neurological problems affecting communication with limited language (either sign language or English)
5. a combination of the sensory impairment and mental retardation.

In the examination of these patients we are at the mercy of the interpreter even more so than usual. We have to learn to appreciate their diagnostic skills in assessing communication, but we must remain aware that their diagnosis in the early stages of an examination is as uncertain as is our own. Difficulties are typically present when we see a new patient and do not have information about the level of communication and language skills, or when the information given in the referral is incorrect.

1. If a deaf-blind patient has had a recent change in vision, it is often the case that the previously used visual sign language is no longer effective. If the patient is inexperienced in tactile sign language, he may appear to see in a large enough visual area and, when asked whether he sees comfortably, may answer "yes". However, he may miss so much of the visual information that he misunderstands some usual signs and/or fingerspelled words. Even an experienced deaf-blind interpreter may misjudge the patient's comprehension in such a situation and thus inform you that the communication should be kept at a rather basic level. During the examination it often becomes apparent that the patient is unlikely to see what is signed and that another mode of communication has to be chosen.

If the patient is accustomed to English, writing large enough letters with a felt-tip pen, using a CCTV, a Viewscan or other magnifying devices can often get the most important messages across. A patient who is primarily an ASL-user can get some information through two-handed tactile signing even without previous experience. In both cases it is wise to limit the examination to tests that do not require complicated communication. After the first examination, the patient and the interpreter can work with the usual sample questions as their homework and come back after a few weeks for further assessment.

2. A deaf-blind patient with known minimal language skills is a challenge if something important and complicated has to be discussed with him, for example symptomless angle closure glaucoma requiring immediate treatment in the hospital. Since it may take half an hour to find out how to describe the situation to the patient, I usually explain it as if I was speaking to a third or fourth grade student. I then ask the interpreter to tell it back to me in English as close as possible to the expressions that will be used in sign language. After clarifying the words that I would stress differently, the patient and the interpreter are left to discuss that part of the information while I am doing something else. When I come back, I

repeat the sentences and they are signed again to the patient. Depending on whether the interpreter and I think that the patient has understood the information, we either rephrase the information once more or ask for a decision about what to do. Sometimes the patient has to make the decision on rather inadequate information, that is, actually knowing only that if the treatment is not instituted immediately blindness may ensue.

During routine examinations of deaf-blind patients with minimal language skills (MLS) the counsellor and the interpreter have usually discussed the worries of the patient before the examination, and we choose only one new important problem to discuss during each appointment.

3. Whenever we are dealing with an additional neurological impairment, we have to work together with an experienced clinical neuropsychologist who preferably has had experience in deafness, if the patient is prelingually deaf. Otherwise, some tests may be chosen that are misleading when examining a visually impaired, prelingually deaf person. Likewise, the effect of restricted vision on some results has to be clearly understood. In these cases it is mandatory that we use the same two or three skilled interpreters during several months or years in order to learn the most reliable ways to transfer information. Because of the limited number of interpreters in this field, scheduling is sometimes a problem. In order to get the interpreter we want to have we may need to arrange the visit on a day we otherwise would not see visually impaired patients.

4. The patient with dual sensory impairment, neurological impairment and minimal language skills is often diagnosed as being mentally retarded. These individuals, however, are able to learn complicated tasks and develop modifications to techniques taught to them. However, they have specific difficulty in comprehension on top of the difficulties in receptive or expressive language. The amount of information that can be conveyed becomes quite limited, and therefore we have to use techniques that we usually use in the examination

of prelingual children. These tests have to be used with the understanding that we are examining a grown-up person with an emotional status and attention span different from that of an infant or child.

5. Mentally retarded, deaf-blind patients without additional handicaps most often cause no major problem in the selection of tests or test situations. They are examined at the level at which they are able to perform. The rate of success in examination is as unpredictable as when we examine young children. We have to be prepared to quickly shift to another test if a certain test does not interest the patient by using indirect information such as VEP-grating acuity values and photorefraction to support or contradict our clinical impression. We must work as a team with teachers, interpreters, caregivers and paediatricians to learn more about the quality of the patient's visual functioning in different tasks.

### **Patients who have forgotten communication**

These patients have typically gone to a deaf school in their childhood and then have lost contact with other deaf persons, often living in an environment with minimal communication, either in their own family or in an institution. If their sensory impairment becomes worse, as in Usher's Syndrome, they may become misdiagnosed as catatonic schizophrenics because they do not react to usual communication and tend to sit in the same place for days. Some patients stay in bed and some have even been fed in bed for years before somebody happened to suspect that sensory impairment may be a large component of their behavior.

You will have these very difficult examinations in the beginning of increased activity in deaf-blindness, since that is usually the time when deaf-blind individuals are found in institutions and brought to your office. These otherwise healthy individuals have often been for years without any communication and may have forgotten sign language. They may even have forgotten what communication means, so that when some contact has been developed it takes months before they remember that ques-



tions are not meant to be repeated back, but answered.

During the first examination there is either minimal or no communication and no information about how much vision might be present. We have to start with simple observations of what the patient seems to notice and whether changes in light levels seem to affect the patient's behavior.

When I read through old records, I ask the accompanying person the usual questions "What do we know about the school and the family of the patient; what was the father's occupation, mother's . . ." and these sentences are signed to the patient with rather small, slow and clear signs even if we have no idea at which distance the interpreter should be. Sometimes one of these common signs awakens the patient to sign something he remembers from the time signs were first used and we have solved our first piece of the puzzle. When we know that there is some vision, we can start making observation schemes to determine the size of the picture in the sign dictionary the person prefers, which techniques are used to locate in a new environment, etc. We continue the examination at intervals of a few months until we get enough information about the patient's vision.

When you have more experience in dual sensory impairment with or without mental retardation, it becomes rather easy to at least suspect that a certain low-functioning person is not functioning at that abnormal level because of mental retardation or psychosis, but because of a lack of information. It is important that the ophthalmologist helps make this diagnosis because some of these individuals can learn to function rather independently even after 15 to 20 years of deprivation.

Ophthalmologists should be especially cautious so as not to misjudge the patient's cognitive development and intelligence. Our schooling in communication is so inadequate that unintentionally we are apt to make gross errors. I dare say this because I can read my own reports written some 10 years ago when I knew how to assess impaired vision, but did not know how to use an interpreter effectively.

Very careful planning and consultations with other professionals, including audiologists, special educators, and the interpreter are often needed before the communication with this group of patients is adequate.

The often written statement "Patient does not co-operate" should disappear from our charts. Co-operation is a two-way street. In most cases, the patient tries his best but cannot reach the communication level of the doctor. Thus it is often not the patient who does not co-operate, but the doctor.

### **Should the Eye Doctor know Sign Language?**

IT is my personal opinion that it is not necessary to be able to use sign language in more than a very rudimentary form. It is necessary, however, to know enough about the structure of sign language and the deaf culture in order to be comfortable in this cross-cultural situation.

There are several sign languages, and patients may use combinations of different languages. Thus, it is difficult to learn to communicate directly with all patients if one does not have continuous contact with deaf culture for other than professional reasons. Limited sign language skills may be dangerous if the doctor starts to believe that he or she can take care of the communication without an interpreter. On the other hand, even limited knowledge of sign language is helpful. Patients usually experience any effort to communicate directly with them as very positive.

Children become much more relaxed when they realize that the eye doctor knows only a few signs and signs them in a funny fashion. They tend to be less frightened by a doctor who is so apparently inferior in communication skills, and they are usually very helpful and good at guessing even ridiculously signed information.

Interpreters have to learn some ophthalmology and optics in order to work in our offices. It is only fair that the medical professional learns as much about sign languages and deaf culture.

## **PART II**

# **Interpreter's Role in the Assessment of Vision**

# Getting involved with deaf-blind interpretation?

INTERPRETING in a medical setting is often interesting but time-consuming because the offices cannot keep the doctors' schedules well-organized. Aside from interpreting in a mental health setting, interpreting in the office of an ophthalmologist is among the most demanding interpretation assignments because so much of the diagnostic work is based on subtle nuances in the patient's answers and because deaf-blind persons value their vision so much.

Ophthalmological interpretation is often a linguistic challenge; it requires fluency in both English and sign language in and outside medical interpretation. Especially in rehabilitation, all kinds of technical terms related to different workplaces, tools, techniques, magnifying devices, mobility and orientation, social, educational, and economic issues are needed daily. That means demanding working conditions which at the same time are seldom boring.

Before anyone makes the decision to become a deaf-blind interpreter, it is advisable to learn to know the deaf-blind community, the ways of communication, one's own reactions created by the unfilled expectations in visual communication and reactions to tactile communication. The involvement is much deeper, much more humane and holistic than in almost any other communication, especially when functioning as the eyes and ears of a totally blind, totally deaf person who has to rely on the interpreter-guide quite differently from a deaf person. The complexity and sophistication of interpretation is on an unusually high level when not only the discussions but everything in the environment should be captured, when you have the challenge of being the deaf-blind person's "mass media" for a few hours.

The deep involvement in the lives of deaf-

blind persons is often rewarding and supportive in the way that we get a new perspective into our own problems when looking at the world through the blind eyes of a deaf-blind individual; deaf-blind interpretation is not, however, to be recommended as a remedy for personal problems.

At the beginning you may be struck by the extremely limited amount of communication that many deaf-blind persons have. There are only a few real deaf-blind communities and outside them deaf-blind persons are isolated both in their work environment and in many families. The situation is changing but slowly for the better. The quality of communication sometimes makes up for the limited quantity. As one of my deaf-blind friends pointed out, hearing people often communicate in ways that the deaf-blind person wants to avoid. We say unpleasant things to each other but are less likely to fingerspell the same kind of unfriendly messages on the palm of a deaf-blind person. There is also less of the very superficial "junk food" conversation that fills many hearing persons' days.

Anyone considering deaf-blind interpretation usually has years of experience of deaf culture and medical interpretation. The visual impairment may make the life of deaf-blind persons different from other deaf persons' lives. The effect of visual impairment on all major areas of daily functions, communication, activities of daily life (ADL), mobility and orientation, and near work like reading, varies greatly depending on which part of the visual field is affected by the nature of the disorder and how profound is the loss of vision.

The demonstration glasses described on page ?? give some idea of how visual impairment decreases the amount of critical visual information in almost all tasks, but they do not convey the disturbances of the image quality that are caused by the changes in the long chain of neural cells transferring visual information from the sensory cells to the brain. It must be constantly annoying to try to figure out whether one can rely on the image that one sees or whether the information should be confirmed



by tactile information, if possible. The numerous misunderstandings and more or less dangerous adventures that are common to both hearing and deaf visually impaired persons will always be a part of the life of the deaf-blind community. If you want to learn to smile and laugh with the visually impaired you may like to read the booklet "Funny Adventures of Sighted Blind" (Hyvärinen & Mehtälä 1986).

After the experiences in the deaf-blind community it is advisable to learn to know the ophthalmological services, especially the few doctors who see deaf-blind patients. When some deaf-blind person is going to have an appointment with the ophthalmologist, you may be able to function as a guide and observe how the other interpreter takes care of the communication and how well the doctor and the interpreter can work together.

The video material related to this book gives you some ideas about visual signing to a patient with tunnel vision. Tactile signing is very different. It is something that everyone learns literally "hands on". The best places to learn it are the deaf-blind communities where tactile communication is a widely-used and well-accepted mode of communication.

In order to use correct classifiers you have to have more than usual college education in the structure and functions of the eye and visual pathways and in eye diseases and visual rehabilitation. You may start by reading the book "Eyes and Vision" written for deaf people and then glance through a nurse's handbook in ophthalmology because it describes the numerous instruments and procedures that you will hear mentioned in the eye clinics.

In the work with the ophthalmologist you will have the need of working with an equal, which may sound strange thinking on today's ranking order. However, the diagnostic work will be so much more rewarding if you can discuss your observations and opinions with the ophthalmologists freely, that you may want to look around for a while, and observe the communication and behaviour of different doctors several times before you make up your mind.

If after all these preliminary investigations you feel hooked you might be the right person to get involved with deaf-blind interpretation. Once you start, you will find that the work is even more interesting and challenging than you thought.

## Ophthalmological examinations

THE focus of this book is assessment of vision and, to some extent, hearing of visually impaired, deaf or profoundly hearing-impaired individuals. Thus, the emphasis is low vision examinations which are easier for the interpreter because the room lights are not switched on and off during the examination and there usually is more room than in many regular offices. However, we must be prepared for both situations.

Doctors are responsible for the quality of examinations in their offices and also communication. However, if the ophthalmologist is not trained in the examination of deaf persons and the deaf patient does not dare to require proper communication, the interpreter is more than usually in charge of the quality of communication. Before the examination starts the doctor and the interpreter have to find out what kind of accommodation has to be made in terms of vision loss.

### Establishing the communication

When the interpreter establishes communication with a new patient in the waiting area, three important variables are observed: preferred distance for communication, size of the communication field and sensitivity to light.

The same three variables are checked in the examination room. The preferred distance is usually easy to find, although sometimes it is difficult to find a space for a chair at that distance. A stool on wheels is handy as the

interpreter's chair because there is often a need to relocate during the examination.

Communication field is described in a very confusing way in all published guidelines for

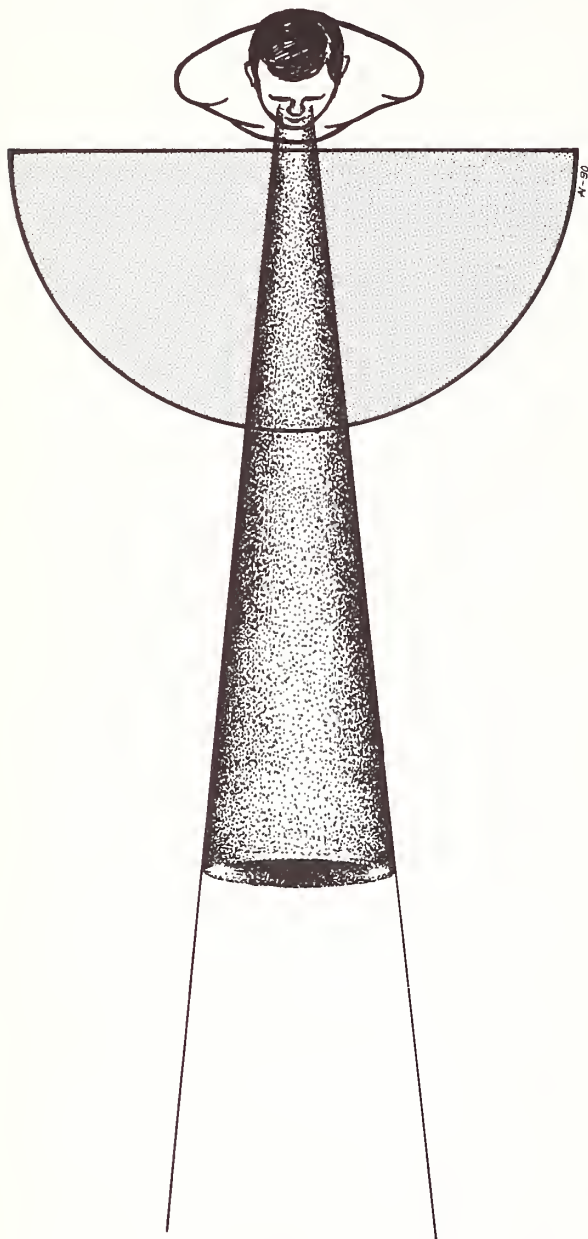
deaf-blind interpreting. In order to understand how changes in visual field limit communication we have to think about the two most common types of loss of visual field: tunnel vision and central scotoma.

"Tunnel vision" gives a somewhat wrong impression of the constricted visual field of patients who have advanced retinitis pigmentosa, choroideremia, or glaucoma, to mention some of the most common causes of small central field. The residual field is often 10-15 degrees in diameter which means that it is 10-15cm (4-6 inches) in diameter at 57cm (22½ inches), 20-30cm in diameter at 114cm, 40-60cm in diameter at 228cm, 10-15 metres at 57 metres and so on. The further away from an object the person with tunnel vision is, the more he can see of it (Figure 6). "Tunnel vision" is not a tunnel but a cone that opens up at a distance.

At the beginning of the examination the area in space seen by the patient can be measured using the technique demonstrated in the videotape: the patient looks at the interpreter's nose and reports when the right hand appears from the right, then the left hand appears from the left, and then from above and finally the right hand from below. If the interpreter touches his body at the points where the communication field ends, he gets a good reference for the size of signs to be used.

The sign for tunnel vision is as misleading as is the written name. We might consider renaming this type of visual field. In sign language it is easy; the sign can be cone-shaped rather than the shape of a cylinder which is typically used.

Central scotoma means a loss of visual function in the middle of the visual field. Since it causes loss of visual acuity, contrast sensitivity, changes in colors and apparently also in motion perception, the person signing has to be closer in order to compensate for the visual loss. It may feel awkward to sign very close and it is often difficult to read the patient's signs at that short distance but during examination there is no other alternative. However, if there is a long discussion between the doctor and the patient and the patient is accustomed to using



*Figure 6. "Tunnel vision" of 15 degrees means that the person sees within 15 degrees of visual angle without moving the eyes. The area available for signing increases the further away the person signing is sitting.*



binoculars, they should be used. Then the interpreter sits at a longer distance that has to be defined.

#### **Demonstration glasses for field defects**

Since it is so difficult to imagine the effect of either tunnel vision or central scotoma, demonstration glasses are often found to be helpful by interpreters, parents and teachers. Demonstration glasses for tunnel vision are made by glueing six short strips of translucent tape to form a triangle (Figure 7). The size of the central triangle is found by trial and error. When you have made the first one, place it on

a pair of eyeglasses, look at a piece of white paper at exactly 57cm distance, and mark the area seen through the central opening. The diameter (in centimetres) of the area seen gives you the diameter of the visual tunnel in degrees. You will also have some peripheral vision, much like a patient with retinitis pigmentosa.

The central scotoma can be demonstrated in a similar fashion by using a small piece of tape in the middle of the glasses and by asking the person to look through that area and not to peek around it (Figure 7). The tape will leave markings on the glasses so you have to be prepared to clean them afterwards.

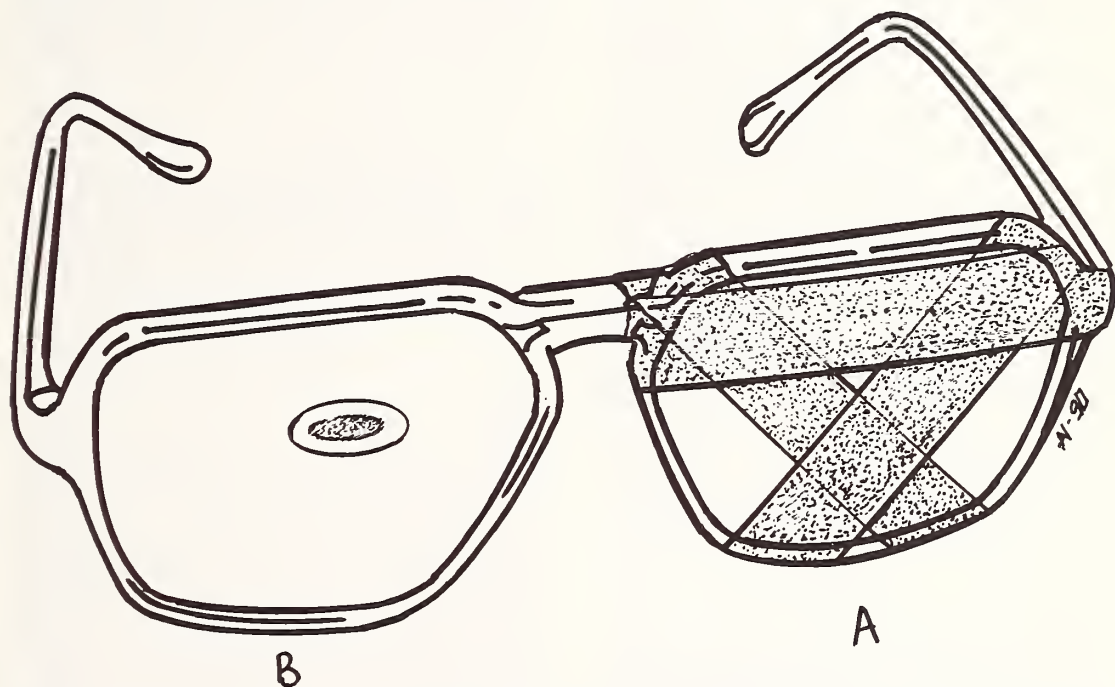


Figure 7. A. Demonstration glass for tunnel vision of approx. 15 degrees (the left lens). The demonstration device is made of a double layer of adhesive tape in order to prevent it from adhering to the glasses. The tape triangle can be fixed on a pair of glasses with small, additional pieces of tape which will not mark the glasses in the middle. B. Demonstration glass (the right lens) for central scotoma: a small piece of adhesive tape, approx. 0.3cm in height and 1.0cm in horizontal diameter, causes a large central scotoma. The depth of scotoma is related to the thickness of the tape. This is about the smallest central scotoma that untrained observers can use when reading. It should be placed on the glasses at the optical centre. Then there is enough blurred area even during the saccades. Smaller "scotomas" lead to peeking but they should be shown briefly to demonstrate the real size of the scotoma that the patient has if it is smaller. This demonstration scotoma usually explains the effect of magnification; it just disappears when magnification is sufficiently high, i.e. when the visual system can extrapolate over the scotoma. Note that these demonstration glasses are best used monocularly; the other eye should have translucent occlusion.

Diffuse loss of vision due to opaque media is easy to demonstrate by using Glad Wrap or a similar plastic wrap, folded eight to ten times. When folding, let small wrinkles form in the material so that you get an uneven loss of information in different parts of the image.

### **Illumination during examination**

Regular bright room illumination is usually adequate for communication. If the lights have to be turned down or off, explanations about what is going to happen must be signed beforehand if the patient is not accustomed to tactile communication.

When the lights are turned on there may be a short period during which the patient cannot see signs well enough, so again some time is lost in waiting for the communication to start.

The walls of many offices are white and therefore not a particularly good background behind the interpreter. If it is possible to arrange a neutral-colored screen behind the interpreter, it may be extremely helpful for many patients. RP-patients with advanced retinal degeneration often complain that an interpreter signing in front of a lightly colored wall may suddenly disappear in a whitish cloud for several seconds. Many patients do not want to interrupt by telling about the disturbance in vision, not knowing that the ophthalmologist would be very interested to learn of it.

### **Clothing**

Recommendations regarding clothing are especially important when interpreting to a visually impaired-hearing impaired person who may be easily dazzled by white or shiny clothing or jewellery. Clothing with stripes or checks may disturb also. Optimal contrast helps the patient to see the signed information and therefore dark shirts with half long or three-quarter length sleeves are best. A dark smock with big pockets is especially useful because the interpreter will often move from room to room and will not want to be concerned about a purse and other belongings.

What is said about the interpreter's clothing is equally true for the doctor's clothing. The

customary white coat may dazzle the patient. In Europe, many specialists in low vision use dark clothing in the office.

### **Relocating in the office**

During the examination there are several situations where the interpreter has to move, either to see the patient's fingerspelling as during measurement of visual acuity at near or to be aligned with the gaze of the patient when the microscope is used.

The offices have not been designed with tactile communication in mind; quite often the interpreter has to squeeze between the instruments in uncomfortable positions, even kneeling on the floor in order to continue communication. If it is possible to use a large room for examination of handicapped patients, it will make the interpreter's work much easier.

As in any communication setting, the interpreter should sit close to the doctor, slightly behind him when visual signs are used. This makes it easier for the patient to change fixation between the doctor and interpreter.

### **Guiding the patient**

Visually impaired, deaf patients cannot orient in a strange place and need help when moving in the examining room or from room to room. It will help the patient to orient in the room if the interpreter can describe the room and the instruments briefly when the patient enters.

Guiding visually impaired persons is something that everyone working in an eye clinic should know, doctors and interpreters alike. If the personnel has not been exposed to training in guide techniques, the local mobility instructors can arrange a short demonstration with one or two of the deaf-blind patients.

### **Breaks**

During examination of vision there are natural pauses; these occur often enough that it is possible to interpret without a break during a complete eye examination. If laboratory tests are done afterwards there is usually some waiting time. Patients accept being left alone for a while if the interpreter informs both the

patient and the receptionist where he will be found if needed before the next test.

### **Scheduling**

Many interpreters work as freelance interpreters. Therefore it is a real problem if they have to wait for the examination. If three deaf-blind patients can be scheduled in one morning it saves the interpreter's travelling time. Deaf-blind persons seldom meet with each other and may appreciate the opportunity of chatting with another deaf-blind person in the waiting area.

Then the time needed for dilatation of pupils will be used in communicating with the other deaf-blind patient and the interpreter is not needed in the waiting area.

## **Ophthalmological Instruments and Procedures**

THE number and type of instruments varies in different offices but the following instruments are involved in many clinical examinations: slit-lamp, retinoscope, phoropter and/or trial lenses in trial frames, ophthalmoscope (both direct and indirect), fixation targets, prisms, tests for binocularity like Worth's four dot test, Maddox's rod, Bagolini's striate glasses, and some of the instruments discussed in Part III of this book.

It is usually best to arrange an introduction to the various functions in the office so that the locations and the use of different instruments are known by the interpreters as well as which instruments usually dazzle the patient and interfere with their vision afterwards.

Most instruments are used without much active involvement of the patient. The direction of the gaze, however, is often critical for a correct measurement or for thorough examination. The interpreter must be located so that

visual communication is possible if something has to be said during the test situation to a patient who is not accustomed to tactile communication. During slitlamp examination and examination of the inside of the eye with an ophthalmoscope the patient has to change the direction of gaze several times and sometimes to extreme positions. The different directions of the gaze can be described to the patient before the examination. The patient can be informed about where to look during the examination by gently tapping at the corresponding area around the eye. This can usually be done by the doctor but if his hands are busy examining, the interpreter can give this tactile information.

Interpreting during surgery under local anaesthesia requires more than routine interpreting skills. The interpreter needs to be instructed on sterility rules and on the strict limitations on moving in the operating room when going to his place close to the patient's communicating hand. Visual communication is usually impossible. Since the interpreter needs the patient's hand for communication, the intravenous drip should be placed so that it does not interfere with the interpreter's work.

The procedure has to be rehearsed well in advance, especially if the patient is not accustomed to tactile information. Then the information given during the operation is reduced to a few simple tactile cues. The interpreter must be informed about the possible effects of premedications on communication. If the interpreter has no previous experience with similar operations he should be present during another operation a few days prior to the surgery of the deaf patient. It is wise to test whether he tolerates the excitement without fainting or any other unpleasant reactions that would be disruptive.

When deaf patients are operated on under general anaesthesia, an interpreter is needed both before and especially after the operation in the recovery area. Again, some instructions on the post-operative care are usually necessary for the interpreter.

Laboratory examinations involve instruc-



tions by technicians who may not be very good at describing the test. It is usually best that the interpreter is tested briefly so he knows what the patient is going to see and when and to what he is expected to react. If the patient is going to press on a button, it is important to instruct the patient that the button cannot be pressed more than once. The typical "yes, yes" answer of a deaf person might disrupt the test.

Measurement of vestibulo-ocular response (VOR) of deaf patients is usually performed in the ENT department but most probably the same interpreter is involved. Communication with a deaf patient in pitch dark without interfering with the test itself is quite a challenge.

The test situation seems to be best understood when the test itself is described first and after that the calibration procedure by saying: "In order to be able to make the measurement we first have to do some preliminary measurements of your eye movements". When the room, the movements of the chair and the fixation lights are carefully described before testing, then communication can be reduced to three different kinds of tactile information, for example, one tap meaning that the patient has to fixate on the light or the imaginary light in front of him, two taps that he has to do the calibration procedure and a slight sweep to "erase" information that was started at a wrong moment. The interpreter is in charge of the lights that have to be switched on and off during the test. The role of the interpreter in this test situation is expanded toward that of a research assistant, but this works better than if an additional person is present to switch the lights in the usually very small room.

## Ophthalmological Terminology

OPHTHALMOLOGICAL jargon uses numerous concepts that are generally unknown

by laymen and have to be explained to both hearing and deaf patients. Doctors vary in their ability to avoid unnecessary medical terms and to explain those terms that have to be used. Any medical term that is used slightly differently from its normal use should be clarified by the doctor; the interpreter cannot be responsible for the often subtle nuances in information related to visual phenomena or eye diseases.

The booklet "Dictionary of Eye Terminology" that has been published recently covers ophthalmological terms well but the explanations given do not always give the information necessary for intelligent signing. For example, "hyperfluorescence" is correctly described as "increased fluorescence" seen in abnormal fluorescein angiography of the retina from abnormal blood vessels, leaking blood vessels, or increased fluorescein transmission". However, when the term is used, the doctor should describe the phenomenon of hyperfluorescence in that particular case, what it looks like in the angiogram and what it means. An interpreter cannot convey the information related to "hyperfluorescence" into sign language without that clarification. Mere fingerspelling of the word is inadequate communication.

There are a number of other terms that are well described in this little booklet on terminology, but which need further study before they can be used fluently. Refractive errors are hard to clarify if a person does not have background in the structure of the eye and optics. There is, for example, a common misunderstanding related to "hyperopia", farsightedness. People tend to think that hyperopia means clear vision at distance but blurred vision up close. It is therefore important to clarify that although the image falling on the retina of a hyperopic eye is blurred when the lens is in its resting position, the image becomes clear when accommodation is used. When distant objects are viewed, less accommodation is needed than when near objects are looked at. Young persons usually have such good accommodation that they can see clearly both at distance and near, even if they are hyperopic.

Similarly, when myopia is clarified, it is important to mention that the myopic eye sees clearly close up, although the image of distant objects is blurred.

Visual acuity values should be signed as they are written, although the "over" is not said. "Twenty-twenty" visual acuity is thus signed "twenty-slash-twenty".

The numerous acronyms used in a discussion between doctors cause a problem. They do not convey information to a hearing patient either but are more disturbing when used in the presence of a deaf patient who might think that the interpreter is not capable of interpreting in that situation. A group discussion is very difficult to interpret except if one of the doctors functions as a narrator of the discussion in plain English.

Condition, situation, and other place holders are common in medical jargon. Firstly, when they have to be translated, it is evident that they actually do not convey a definitive message. The meaning changes in different contexts. Therefore the interpreter cannot start interpretation before there is enough information for deciding the meaning of the "mush word". Since this causes delay, poorly defined words should be avoided.

"Immediate family" is one of the expressions seldom used in regular English but quite often discussed in medical settings. Whenever this or similar expressions are used and the meaning is even slightly unclear, the doctor should clarify what exactly is meant in this case. Genetic questions are often discussed during ophthalmological examinations and therefore genetic vocabulary and the ways of discussing family trees and modes of inheritance should also be discussed between the doctor and the interpreters early during the collaborative work.

In the book "Eyes and Vision" there is a list of questions that often occur during assessment of low vision. The content of these questions should be well known by every interpreter who is assigned to work in an ophthalmologist's office.

These questions will be signed in the videotape "Eyes and Vision" that we hope will be

released within a year. This tape may serve as a model but, of course, different modifications will be necessary to meet the individualized needs of deaf patients.

## **Questions**

### **1. Vision in twilight.**

Do you see poorly in twilight and at night?  
If you wait in the dark, do you start seeing better?

How long a time do you have to wait?

When you go into a dark room, does your field of vision become smaller?

There is often very little light on the buses and trains. Is it difficult to see there, on the buses and trains?

Is it difficult to go from a bright light to a place in shade?

When you go into a shop, do you have to stop at the door and wait for a while before you start to see in the shop?

### **2. Light sensitivity, dazzle.**

If the sun is shining into your eyes, does your vision become much worse?

Does the sun dazzle you for a long time? How long?

Does bright light cause pain in your eyes?

Do you use sunglasses? Goggles?

Do you have several (2-3) different pairs of sunglasses?

Do you bump into people even if you have your sunglasses on in bright light?

Do car headlights dazzle you?

### **3. Disturbances related to motion.**

Is it difficult to move in places where people walk close by?

If you walk in a place where the wind moves branches of bushes and trees, does the movement of the branches bother you?

If you turn your head quickly, does it bother your vision?

If movements disturb your vision, what happens in your vision when it becomes disturbed? How does it change?

#### **4. Contrast sensitivity.**

Can you see the curb?

Can you see the stairs when you walk down-stairs?

Should all stairs have contrasting edges?

Do you see the poles of the traffic signs in time to go around them?

Is it difficult to see light colored food on a white plate?

Has it become more difficult to lipread and see fingerspelling?

Is the newspaper text difficult to read because of the light print?

#### **5. Illumination.**

Can you sit facing the window?

Do you find small focal lights, like candles, disturbing?

When you read, how do you want to arrange the lights in the room?

Do you have a special reading lamp?

What color of light is most comfortable for you? Do you use filter glasses (tinted glasses) when reading?

Does extra light make reading small print easier?

Did you look around at home and think which lights should be moved to another place? Where would you like to have more light? Are the street lights strong enough? Do you need a flashlight?

#### **6. Visual field.**

How large an area do you see in front of you? Has it happened that you misunderstood a situation because of loss of vision in parts of your field of vision?

When you look straight ahead and move your hand by the side of your head, can you see your hand moving?

Do small objects disappear from your vision and pop up after a while?

When you read, can parts of the letters disappear?

If you use sign language, does the person

signing have to go further away to be seen? If the interpreter sits at a distance of four feet, how much do you see of the interpreter without moving your eyes?

#### **7. Visual illusions.**

Is there flickering of the picture (image) in any part of your field of vision?

Do you see lights moving around near the blind areas of your field of vision?

Are there any other lights moving in the visual field? What do they look like?

If you cough or laugh, does the image change?

If you see lights moving across the visual field, do you see your surroundings as through a frosted glass? Or does the image disappear? Do straight lines become different? How?

#### **8. History of the disease.**

When did you notice the first changes in your vision? Before school age, at school, after school?

How rapidly did the changes develop then?

Has there been any change in your vision during the last year?

During last five years?

Has there ever been a period of very rapid progression of the changes? When? How did the vision change then?

Have colours become different?

Do you have difficulties seeing any colors?

Has your reading speed changed? How much? When?

Do you have pain in your eyes?

#### **9. Visual aids.**

Do you have several pairs of glasses? (If you do have, please, bring them all to the office. Also all other visual aids.)

Do you have tinted glasses? Sunglasses?

Do you use magnifying lens(es)?

Do you have a telescope?

Do you use any other visual aids?

Which visual aids would you like to try this time?



# Devices used by Deaf-Blind Persons

DEAF-BLIND persons with residual hearing and/or vision may use a wide variety of different devices for communication, for getting information as written information, print or braille, for awareness of sounds in their environment, etc.

Because the book "A Complete Guide to Communication with Deaf-Blind Persons" by Linda Kates and Jerome Schein is now available, there is no need to discuss all the devices used by deaf-blind people because most of them are included in that book. Some new devices

were mentioned in chapter IV and are depicted here.

## Optacon

Optacon II provides access to the printed word and to electronic information via its RS-232 serial interface. As before the device has three components: a small hand held camera (1) that "sees" the print and sends the information to the control unit (2). The control unit processes the information and gives a tactile array (3). The tactile array consists of 100 vibrating rods.

The deaf-blind person moves the camera across the line and perceives the vibrating image with the index finger of the other hand.

## Videomagnifiers

Videomagnifiers or closed circuit television systems, CCTVs are expensive but useful magnifying devices when optical magnification

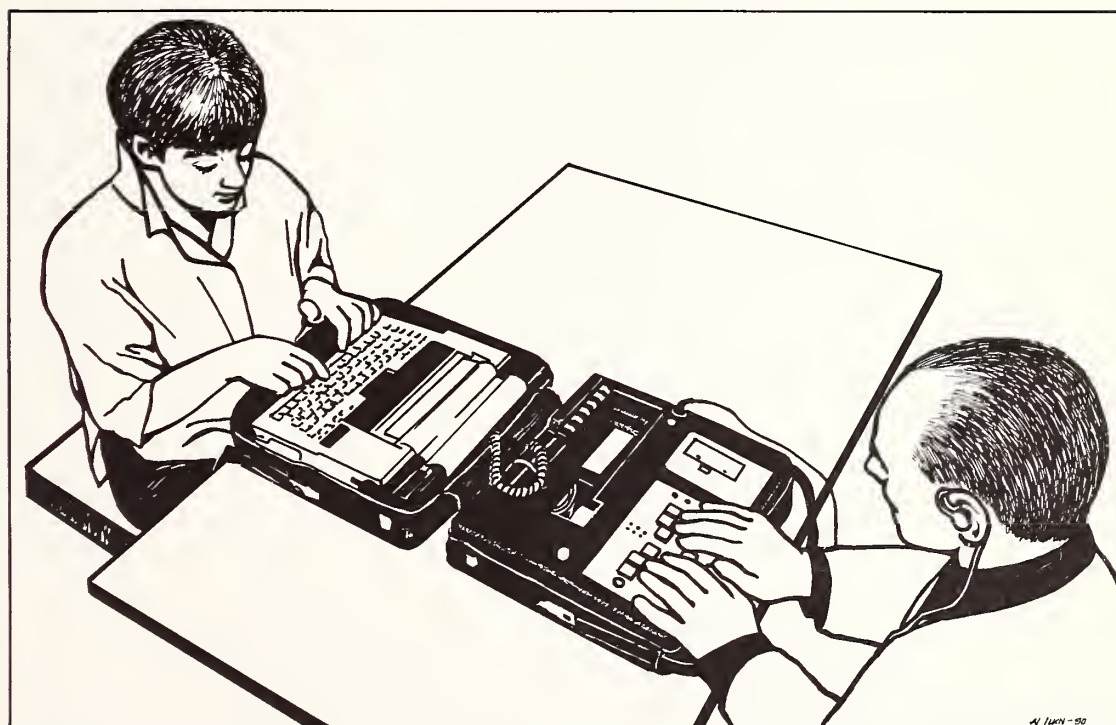


Figure 8. "Dialogos" enables a deaf-blind person to communicate with other persons using either typing or braille. Braille information is received by placing hands on the dark keys that have a pin in the middle of each key. The pins pop up and therefore require much less tactile sensitivity than regular braille print. "Dialogos" can be used as a telecommunication aid as well.

is ineffective. If the patient has lost visual function in low contrast domain, CCTV is the only device that can improve the contrast of the reading material. Most often the patient then prefers a reversal image, white print on black background.

#### **Magnifying systems for screens**

There are numerous different modifications to computers to enlarge the text on the screen for visually impaired users. The work can be further supported by voice for those persons who can benefit from auditory information.

#### **Communication devices**

In addition to the numerous communication devices in the book "A complete Guide to Communication with Deaf-Blind Persons" there is a new Finnish device "Dialogos" (Figure 8) for deaf-blind people. It consists of a braille console, an electronic typewriter and a tape recorder.

Interpreting during the demonstration and training of these devices is very difficult if the interpreter has no previous experience with their use. The interpreter should always have an opportunity to experiment with the device for a while before trying to convey the often very technical explanations.



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AFB Deaf-Blind Project  
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# **PART III**

## **Tests and Techniques**

# I. Oculomotor Functions

OBSERVATIONS of oculomotor functions are usually done briefly in the beginning of the examination and in depth after the assessment of visual acuity, contrast sensitivity and the structure of the central field of vision.

Whenever a patient uses extrafoveal viewing, it has to be explained to the interpreter at the beginning of the examination, otherwise he will be confused by the seemingly poor contact with the patient.

Examination of fixation pattern and alignment of the eyes is difficult in young deaf children because they fixate very briefly on a new target after which they fixate either on the doctor's interpreter's, or parent's face. A person signing is the best distant target. For near testing, a test target that can be rotated, such as Lang's cubicle, or one that changes when tilted may hold the child's attention long enough for version and vergence movements and the cover test.

Many different disturbances of oculomotor functions are common in congenital visual impairment, but nystagmus may occur also in near-blind individuals who have had normal motor functions and normal vision as children.

If the hearing impairment is complicated by balance disturbances, the vestibulo-ocular reflex may be absent as in many patients with Usher's Syndrome Type I. Some patients use pursuit movements to compensate for the lack of VOR so well that they seem to have normal VOR if briefly observed during a few pendular rotations of the chair used for testing.

Abnormal head postures may be related to compensation of a phoria or blocking of nystagmus with a head turn or with a downward gaze, but looking "out of the corner of the eye" may also be related to compensation of refractive error by creating a pinhole.

Assessment of binocular status may be misleading at this point if a penlight is used for

fixation. The patient may be able to fixate centrally on a penlight but will use an extrafoveal fixation point for reading and for other tasks that require optimal resolution. Also, small angle tropias are often missed at this point because the patient cannot differentiate between blur caused by the basic sensory disorder and blur related to small angle tropia.

Binocularity becomes a very different issue when central vision of both eyes is abnormal. If peripheral fusion holds the eyes straight, the patient may be disturbed by two images that are centrally distorted in different ways. Often, in these cases a workable solution is distance correction in one eye and near correction in the other eye. In this manner the area of fusion is usually eliminated. A number of visually impaired children with equal impairment of vision in both eyes, learn to use one eye for distance vision and the other eye for near vision if they get this correction early. It will be beneficial later in life if one eye can be fitted with a telescope and the other eye with a reading lens.

If the hearing impaired patient uses an unequal correction, that is, one eye with distance correction, the other with near correction, we have to change one or both corrections to match the correction used for communication at the preferred distance if vision has changed.

Accommodation is sometimes weak or even absent in patients with congenital visual impairment and/or with cerebral palsy. Therefore, near correction may be needed for communication within one metre's distance, even in children.

Accommodation and convergence are closely related but can be impaired independently of each other. Accommodation may be present without convergence, which is rather common, or it may be extinguished when convergence is normal, which is rare. Miosis when the patient is using near vision is sometimes hard to see and sometimes is not present because of synechiae. In doubtful cases, the absence of accommodation can often be demonstrated when one compares visual acuities at different distances using different refractive corrections.

# Visual Acuity

## Refraction

BEFORE visual acuity can be measured we firstly have to measure refraction. Again, it is best to use either the interpreter or another person signing as the fixation target in order to maintain communication, if the patient sees with both eyes.

In a number of cases, objective measurement of refraction is difficult, unreliable, or impossible because of distortion of the image in the optical media, uncertainty of retinal location used for viewing, miosis or other causes that block the passage of the beam. In these cases, subjective refraction should be mastered by the examiner.

Uncorrected large refractive errors are common among hearing and visually impaired persons, especially when they are low functioning. By large refractive error, I mean sizable errors of up to 10-15 diopters. If the first +10 diopter lens placed in the trial frame does not change the near point, you may need two more in order to bring the image within near vision. Likewise large uncorrected myopia is quite common. If the patient cannot answer during

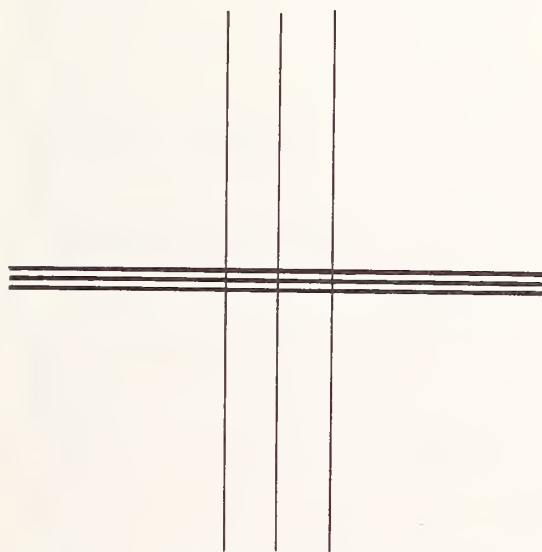


Figure 9. A simple cross for subjective assessment of astigmatic errors.

testing for the best subjective correction, one may use grating acuity measured using VEP technique as the response.

Once the near point has been found, the presence of astigmatic error may be found using a simple picture of a cross that the patient himself can move so that first the lines in one orientation and then the lines in the other orientation are sharp. A measure stick with dioptric markings facilitates the estimation of refraction.

Many patients use one area of the retina for viewing in near vision tasks and another for distance vision. Also, in cases where the fixation seems to be central and the same for both distances, astigmatic correction may change at the different distances. The importance of astigmatic correction varies. It is often surprising to notice that the patient may be able to reliably demonstrate the presence of astigmatic error when tested with the cross, yet when reading he does not notice a difference when the axis of cylinder is changed 90 degrees. Unnecessary astigmatic corrections should be avoided.

The question "Which is better, the first lens or the second lens?" used during subjective refraction is confusing in sign language because the sign "better" is a derivative of the sign "good". If neither of the two alternatives is "good", how can the patient determine which is "better"? After such a question the answer is usually "Neither", after which the next question is "Any difference?". It is often possible to adjust the correction of a hearing impaired patient as finely as with hearing, visually impaired patients. In many cases, even the cross cylinder can be used with great exactness. The two choices have to be signalled by the examiner to the patient tactually, for example, one finger placed on the hand of the patient meaning first alternative and two fingers for the second alternative.

Before we use the cross cylinder, it is best to give the cross cylinder to the interpreter or demonstrate the use of the cylinder near the interpreter when the test is described.

Refraction is often forgotten even when an examination has been made under anaesthesia



for better visualization of the structures of the eyes. However, even if a large refractive error has been found, it is quite common that the multihandicapped person has not obtained the needed glasses. The reason for this is often stated in the question "Why give 20/20 vision to a 20/200 brain?". This unfortunately all-too-common attitude is a disgrace to our profession. A person with difficulties in the analysis of the visual image needs the best possible quality of image if we want him to learn at optimal level.

### **Optotype tests**

The group of deaf-blind patients covers all age groups and all communication levels, and thus we have to be prepared to use all available tests and to create new tests and testing situations when nothing seems to work. This chapter will deal with the usual examination in the office. The assessment of vision in severely multihandicapped children and adults will be discussed in separate chapters.

Visual acuity tests using optotypes are linear tests, single symbol tests, or tests with crowded symbols. Low vision clinics and individual eye specialists serving the visually impaired patient are now quite modern in their visual acuity testing, i.e. they use new charts designed according to the principles published by Bailey and Lovie (1976) and recommend by the Consilium Ophthalmologicum (1988). There are now several tests with minor differences in the form of the letters, being the Sloan, Snellen or British letters. Projected charts should not be used because the room lights have to be too dim, the difference between the luminance level of the chart and that of the face and hands of the interpreter is too great.

For children there is a complete set of visual acuity tests, the LH-visual acuity test system, that is based on four symbols that blur equally (Oriola, Espoo, Finland). For young children and mentally retarded children there is a set of three-dimensional forms depicting the LH-symbols, so that the forms can be trained before the assessment (available at Zentralverein für das Blindenwesen, Schützengasse 4, 9001 St. Gallen, Switzerland).

Near vision tests recommended for assessment of abnormal vision should be based on the same letters as the distance charts and have the same basic layout.

Visual acuity tests are designed for a certain distance. Patients with abnormal vision have varying preferred distances for sustained near work. Therefore the testing of visual acuity should be done at the preferred distance and with the preferred head posture. The visual acuity value is then calculated as a function of distance.

Communication during measurement of visual acuity in near vision is often problematic because the patients fingerspell the letters close to the test. The interpreter may have to stand up to see the fingerspelling. As it is impossible to inform the patient about the test when he is looking at it, I prefer to use a card with which I can cover the lines above or below the line to be read. In this case there is seldom any misunderstanding about what to look at.

### **Grating acuity**

Infants and older patients who cannot answer in optotype tests, can be tested by using small objects or grating targets and observing what is the smallest object or the finest grating that the child shows a response to. These acuity values are different from values measured as recognition acuities with optotypes. In abnormal visual systems, and possibly also in the developing visual system, the ratio between optotype acuity and grating acuity varies greatly (Hyvärinen 1983). Even in a normal visual system the ratio between these two acuity values varies at the different acuity levels (Hyvärinen et al 1987).

Whenever grating tests are used, the acuity values should not be given as optotype acuity values. The grating acuity values, which are given as cycles per degree (cpd) are confusing at the beginning but worth getting used to since this measure is used in contrast sensitivity tests, too.

### **Standardized word lists**

Reading high contrast print requires recog-



dition of symbols that are closer to each other than symbols in a line test. For children who cannot yet read there is a test with crowded symbols as a part of the LH-near vision card N2. For older children and adults we need standardized word lists. In English there is a word list with words of different lengths. Since the words have to be fingerspelled, the test situation is quite difficult for the interpreter: the words cannot easily be learned by heart and there is little time to check from a copy of the test. Reception of independent words fingerspelled by an unknown person is a very demanding task.

### **Reading of continuous text**

A text used for testing reading ability of a person with low vision should be standardized to be equally difficult throughout each page of the test. Tests for the deaf population should contain words common in "deaf English" and they should have texts at different grade levels. Since such a test was not available when we started our project, we tried to write material for testing reading but found it too difficult. We might have to be satisfied with texts written for hearing students at different grade levels and standardized for their difficulty throughout each page.

## **Contrast Sensitivity**

MEASUREMENT of contrast sensitivity has yet to become accepted as a routine test. Although there are numerous reports on new insights that measurement of contrast sensitivity may give regarding the nature of abnormal vision and its use in assisting diagnosis, clinicians have not embraced the new tests which are now available.

Deaf persons using visual sign language are dependent on low contrast information in many

communication situations where no special attention is normally given to the contrast between clothing and hands. Lip movements and fingerspelling involve low contrast information in motion. Assessment of visual function in the low contrast domain is therefore of particular interest in deaf patients.

### **Contrast sensitivity tests**

Those who have not had experience with contrast sensitivity tests may benefit by a short description of the tests and what these tests measure. Contrast sensitivity refers to the ability to discern small luminance differences present in adjacent surfaces. It can be measured in many different ways.

### **Grating tests**

The technique most often used in research laboratories presents displays of grating patterns generated on an oscilloscope screen where mean luminance, exposure time, movement etc. can be controlled. The gratings are either sine wave or square wave gratings. By using gratings of different spatial frequencies (with different numbers of lines per degree of angle of vision) contrast sensitivity may be measured at each spatial frequency, and this allows the determination of what is called contrast sensitivity function or contrast transfer function.

The contrast sensitivity function can be measured in another way. Instead of a fixed spatial frequency we may choose fixed contrast and measure the highest spatial frequency seen by the subject at that contrast, that is, we can measure grating acuity at different contrast levels. This technique seems to be better than the classical contrast sensitivity measurement in clinical work, the definition of threshold is easier for the patient (Hyvärinen 1990).

### **Commercially available grating tests**

There are several commercially available printed grating tests and a few tests based on use of a computer. In the assessment of deaf patients Vistech's and Clement Clark's tests function well. Both of them have some limita-

tions that should be understood by the user. Vistech's test stimulus is 1.5 degrees at three metres distance. Even if brought to one metre the size of the stimulus does not become larger than 4.5 degrees. Only the three lower lines of stimuli contain a high enough number of cycles, the two upper lines are useless. With the Vistech's test one can define the upper location of the curve but cannot define the declination of the slope with sufficient accuracy.

Clement Clark's contrast sensitivity test contains a sufficient number of cycles but it, too, is only 2 degrees in diameter at six metres, which is an inconveniently long testing distance. Although it has only one frequency, it gives the same information about the location of the upper end of the slope as does Vistech's test. Clement Clark's test has a demonstration plate at 13% contrast, while the highest test plate is at 5% contrast. Some visually impaired persons do not see anything except the demonstration plate and an occasional patient does not see that either. Since we need grating test values between 13% and 95% contrast it would be of great practical value if a test plate at 25% contrast could be added to this otherwise handy test.

Mentor's B-VAT II-SG and Frisen's ring perimeter are promising new instruments that may make it possible to assess contrast sensitivity in different ways. It will be a great improvement when grating and optotype tests can be used on the same screen. Both instruments are in a stage of rapid development at the time of writing so they are not described in detail.

### **Printed optotype tests**

Contrast sensitivity can be measured with low contrast optotypes. Printing of low contrast optotype tests with the required accuracy in contrast rendition is extremely difficult, especially at the lowest contrasts needed. Most commercially available low contrast optotype tests, like the University of Waterloo near vision card and the new Bailey-Lovie charts, have test materials between 95% and 10% contrast. The Pelli-Robson low contrast letter chart is the first printed high quality optotype

test. It uses one letter size corresponding 0.03 or 20/670 at the test distance of one metre.

LH-5 contrast visual acuity test contains five pages of low contrast photographic copies of the LH-visual acuity chart. It is the only optotype test with which it is possible to assess the whole slope. Values measured with the LH-5 contrast test are closely equal to those measured with Mentor's B-VAT.

### **Tests for young children**

The LH-5 contrast test uses optotypes that were developed for measuring visual acuity in children. At low contrast they are less interesting than at high contrast and thus it is harder to entice the child to perform close to threshold. The test can be used from about 3-4 years of age but the younger child needs praise after each answer.

The new "Mr Happy" test developed by Ian Bailey functions very well in both a preferential looking situation and when asking an older child or low functioning adult to point to "Mr Happy". As with the LH-test, it gives the parents and teachers an opportunity to see what kind of picture their child can perceive. This is a very important piece of information for both communication and learning.

Our experience with this new test is still quite limited but it seems to offer a nice addition to the test battery for assessment of children and low functioning adults.

### **Communication during testing of contrast sensitivity**

Communication in sign language has not been a problem when measuring contrast sensitivity in a number of deaf persons with Usher's Syndrome, a congenital loss of hearing and later a developing loss of vision due to retinal degeneration. The optotype tests are used the same way as when measuring visual acuity at high contrast. Grating tests require that the patient either shows the direction of lines with his hand, which is easy, or answers on which of the two pages in the Cambridge test the grating is located.

# Visual Field

AMONG all clinical tests the results of usual visual field measurements of deaf patients are the least reliable. The reason quite apparently is inadequate communication because deaf patients are visually more alert than hearing persons and likely to perform exceptionally well in vision tests, if they know what their response should be.

Tests for the measurement of visual field are the regular tangent screen and Goldman perimetry or automated perimetry with minor modifications. If the clinical examination is started with careful measurement of confrontation fields for "communication field" and that information is given to the laboratory, we usually get repeatable results. Another cause for variation in the size of visual fields is visual adaptation. If the patient is tested after different periods of adaptation to room light the size of the field varies in many cases of retinal degeneration. When visual fields are measured for research purposes it is essential that exposure to bright light prior to the measurement is carefully avoided for several hours.

Use of the perimeter tests requires explanation of the test situation to the interpreter. If both the interpreter and the patient are new, it is advisable to demonstrate the test by first briefly measuring the visual field of the interpreter. This gives the patient an opportunity to observe what is going on and it makes it much easier for the interpreter to describe the testing situation. In retinitis pigmentosa, Goldman perimetry is often a lot easier than the automated perimetric tests because the flickering, spontaneous lights that these patients see are hard to distinguish from the small flashing lights of the automated perimeter.

There are no widely accepted guidelines on how we should measure the visual field in retinitis pigmentosa. The difference in the size of the isopters IV/4 (or V/4) and I/4 is a measure of the loss of retinal function at low photopic luminance levels. The area of visual field that does not respond normally to the I/4-stimulus

is, as a coarser sieve, unable to capture finer details of visual information.

The size of a ring scotoma should be roughly estimated in the office prior to laboratory tests. This otherwise difficult measurement is easier if we know approximately what we are looking for. Quite often deaf patients are unaware of the structure of their visual field and have unnecessary worries about their vision because objects disappear and reappear in mid-periphery. This question was included in the teaching tape with the hope that it would be explained regularly in the future.

Examination of Goldman field in young deaf children requires a skilled technician and plenty of time. When I examine the fields myself, which I do if there are any difficulties, the first fields are of no use, the second fields measured a few weeks later gave a general idea about the structure of the field and the third fields measured again a few weeks or months later can be rather reliable. However, it is my experience that the isopters, measured in Goldman perimetry, often tend to grow between 6 and 9 years of age although it is more likely that there is slow constriction. This means that the child learns to communicate with us better and also concentrates better in the test situation.

If the patient has a small tubular field, it is easier to assess using regular white paper at 57cm distance, or at 114cm if the field is very small. At 57cm, one centimetre on the surface is equal to one degree of visual angle. The patient fixates on a cross in the middle of the paper and responds when he sees the black target, a simple black pen, coming from the side. This may sound unsophisticated, but the field measured with this technique is closely equal to the IV/4- isopter of the Goldman fields. The size of the field in degrees is equal to the size of the area seen, measured in centimetres.

Some patients experience changes in the size of the visual field at different luminance levels. In order to record this we can measure visual field first on a white surface (usually at 30-50 cd/m<sup>2</sup>), then on a black surface (somewhere around 1-4 cd/m<sup>2</sup>) and finally on a lightbox



with a 1000-1500 cd/m<sup>2</sup> luminance level. The size of the field may be exactly the same in all of these three conditions or it may vary by becoming smaller both at low and high luminance levels or only at a low luminance level.

### Visual fields and legal blindness

There seems to be considerable confusion among the parents and teachers of Usher youngsters regarding the size and quality of the visual field. Since these children would not otherwise get the services they need, it often seems that the size of the visual field is reported as being smaller than it actually is so that the child can be classified "legally blind". This is a sad and counterproductive situation that needs to be changed. Decisions related to eligibility for services should be made by experts in the field of deaf-blind rehabilitation, and should not be based on a single number. The present practice unfortunately leads to very strange situations. For example, children with beginning ring scotoma, when the I/4-isopter is still 60-80 degrees in diameter, are given cane instruction for daylight mobility. The child, who can see may get a very distorted idea of him- or herself, not understanding why he is being taught cane techniques. In some cases the child's resistance in not accepting the cane has

made the teacher and parents talk about the ensuing blindness so much that the child becomes afraid of losing his sight in near future.

One of the cornerstones of rehabilitation is that the patient is taught what he has to live with. Without this knowledge he cannot be in charge of planning his future. Parents and teachers must also get accurate information in a form they can understand and use in everyday situations. It is very difficult to explain the structure of the visual field in detail, but most often the explanation given in our teaching videotape is quite satisfactory as the first round of information. Understanding makes the patient and the parents more alert, since the more they know, the more they are likely to remember and report observations and be eager for more information and explanations from the doctor.

### Central scotoma

Central scotoma is often ill defined, patchy, the image distorted and discoloured. A good assessment of this visual problem is not easy to achieve. The use of the Amsler grid as the first test is particularly useful when examining deaf patients since it is rather easy to explain and it can be done by the patient over and over again while waiting for other tests.



*Figure 10. Blinking stimulus that can be turned on and off is a good test target for confrontation field and as an introduction of visual field testing. This device was produced at the University of California, Berkeley, School of Optometry.*

If the regular Amsler test does not reveal central scotoma but there is metamorphopsia of the image, testing in reduced illumination, at a level where the grid can barely be seen, may demonstrate the scotomas better. This can be done by using a dimmer or, if reproducible test conditions are needed, by using cross-polarizing filters.

An exact measurement of the size and configuration of central scotoma on a tangent screen requires good fixation. It is facilitated by using a cross similar to that used in the Amsler grid.

### **Assessment of visual field in young and low functioning patients**

Normally sighted deaf children are usually very alert to visual information in their peripheral vision. Test objects that appear from behind the patient are noticed quickly. The test situation is the same as that used when examining normally sighted, hearing children. If the child is old enough to respond to the wand moving within the visual field, it is helpful first to show the child that the blinking light can be turned off. Then the wand is moved back and forth in an area of the visual field which is likely to function normally. The light is turned on and off and the child is requested to sign "yes" every time the light blinks. In this way we learn how good an observer the child is. When this part of the test is successfully completed, we can start examining other areas of the visual field, again asking the child to answer each time the light blinks. The very same technique is used in the office examination of many adults as an introduction to Goldman or automated visual fields.

When we measure the visual field in low functioning, multihandicapped children, there are numerous sources of errors. The observations on the size of the visual field should always be made in a play situation where the child or the adult is at an optimal activation level. If the cognitive development is below 6 months of age, lack of attention to peripheral information may reduce the apparent size of the visual field as it does in normal infants during the first few months of life.

## **Colour Vision**

COLOUR vision tests to assess changes due to acquired colour vision defects have to be of the type D-15, saturated and desaturated, or 100-hue. These tests are difficult to handle if the visual field is limited or when the patient has central scotoma. Also, the size of the caps are so small that the stimulus becomes too little in many cases of central scotoma.

We have used Gunilla Haegerstrom-Portnoy's modification of the standard colour vision tests with success. The modification uses the same Munsell papers as the regular tests but is made in the form of 3x3" plates with four dots on each plate, three similar, one different. The colours are chosen to be on the confusion lines of dichromats. The test is quick and there is no danger of damaging the test because of difficulties in seeing the exact location of the cap. They also seem to function well with young children. The experience with these plates is too brief to allow conclusions on specificity and sensitivity at the time being.

Our teaching video shows the standard test situation with both the plates and the desaturated colour vision test.

If inherited colour vision defects are screened, the regular Ishihara and HRR can be used with no difficulty in the examination of deaf patients.

## **Visual Adaption**

VISUAL adaptation is the most often altered visual function in retinal diseases. The change may affect either the time course of adaptation, the range of adaptation or both. Depending whether cones or rods are more affected the problems of delayed or restricted adaptation occur predominantly in photopic or scotopic conditions. Quite often patients who are light sensitive and easily dazzled due to changes in retinal function, also have small subcapsular

lens opacities which cause increased scatter of light and worsen the condition further.

Usher's Syndrome is the most common cause for adaptation problems in the deaf-blind population. It is often described as night blindness but naturally occurs during daytime as well if there is a marked change in luminance. This is often forgotten when assessing school children. Some of the Usher youngsters have such slow adaptation that it may take them 20-30 minutes before they start seeing in the classroom if they have been in bright sunlight. Finding objects from cupboards and closets may be impossible in the home economics class. If these problems are not noticed and dealt with we force the child to function tactually without having taught the use of tactile information. The same problem is common in many work places where some observations or tasks must be done in mesopic range of vision and the change of luminance is rapid.

Our present tests give rather little information for assessment of delays in visual adaptation. I have used a set of plastic cards, blue, red, and white (Thornton 1977) for screening and also for preliminary assessment of delayed and/or reduced cone adaptation of deaf children. This test is useful in the schools and homes of deaf children informing the teachers and parents how rapidly the child starts seeing colours when entering a dimly lit area. For diagnostic use we need similar but better standardized tests.

Goldman-Wecker's adaptation test gives us information on both the delay and the final threshold of visual adaptation. The usual execution of the test can be modified when examining young deaf children by covering one eye for half an hour and measuring only the final threshold. If the child does not seem to understand the test when in the dark, we can cover the dark-adapted eye in the dark, then turn on the lights and explain again to the child who now watches with his less adapted eye and then continues the test in the dark.

During the measurement of visual fields at different luminance levels we also learn something about visual adaptation. In most cases the

size of the visual field reaches its maximum within half a minute. We may observe some increases at the points measured as the very first ones. In other cases there is a slow increase in the size of the visual field over 3-4 minutes and fluctuation in the thresholds which would make the patient "unreliable" in automated measurements.

The tests for glare sensitivity and glare recovery suitable for examination of low vision patients are not commercially available. The test target should be designed so that it can be seen by patients who have lost some of their central contrast sensitivity.

### **Absorption glasses**

If our clinical tests for visual adaptation need improvement, our testing for absorption glasses needs to be built starting from its foundation. Today the prescription of absorptive lenses is based on the patient's subjective experience when the lenses are demonstrated. Often this is done in room illuminance or while the patient is looking through a window. Usually we have no proof that we have given the best possible prescription for absorption lenses.

Absorptive lenses are either filter lenses that cut out a part of the spectrum nearly totally or totally, or lenses that reduce transmission of light at all wavelengths almost equally. Some of the lenses are phototropic. We thus have four basically different types of lenses: filter lenses and non-filter lenses both of which can be phototropic or have only one transmission level.

Ever since Corning introduced the CPF-lenses there has been much discussion concerning which patients should have these more expensive photochromatic filter lenses. When we try to answer this question we should know what happens in the retina when the filter lens is placed in front of the eye. The total amount of light is reduced so that the eye's adaptive state is changed slightly toward lower photopic range. This same change can be achieved with any absorptive lens. However, simultaneously there occurs another change that we know very little about: blue cones and



rods are selectively brought to mesopic luminance levels while green and red cones function in photopic conditions. Depending on which filter we choose, the effect on illuminance available for blue cones and rods will vary. It may be the reason why different patients experience different filters better than other almost similar filters.

The change in the quality of the image that many RP-patients describe, when looking through CPF- or similar lenses, sounds as if the filter would stop the rods making noise. Now there is a possibility of assessing the filter effect more carefully when we can separate the effect on luminance from the filter effect.

Corning has kindly made available a set of balancing filters that, combined with the original CPF-filters, will change the total transmission of CPF-511 to either that of CPF-527 or CPF-550 and the transmission of CPF-527 to that of CPF-550. The use of the balancing filters allows us to compare the filter effect of the different lenses without simultaneous changes in luminance that these patients are very sensitive to.

Since we have no tests for selecting absorption lenses, the best way to make a sensible choice is to have as many absorptive lenses as possible for comparison during a camp or weekend gathering for the deaf-blind. We have used the skiing camps in March and the family learning vacations during the summer in Finland for this purpose. When the different absorptive glasses are compared at different times of the day in full sunlight, in shaded areas and when moving in and out of buildings the patients learn the typical features of each lens and make very well founded decisions on what to use.

### **Photochromatic or nonphotochromatic lenses**

The photochromatic filter lenses are more expensive than the non-photochromatic and therefore there has to be a good reason for prescribing them. When the type of filter has been decided upon, I lend the corresponding commercially available photocromatic clip-on pair and the corresponding tinted plastic lenses

for a week or two weeks after which time the patient is asked to describe what is good and what is problematic in both lenses. If the photochromatic feature is considered important enough, the patient gets the photocromatic lens. If it is not appreciated, the patient usually prefers having the lighter weight plastic lenses.

## **Examination of Multi-handicapped Deaf-Blind Children**

MULTIHANDICAPPED children are a challenge in medical diagnostic examinations. Communication is often so complicated and highly individual that most sign language interpreters cannot help us. The caregivers, parents and teachers are the persons who know how to ask questions and how to interpret responses. So our approach in examining the multihandicapped children is very different from our usual clinical work: instead of examining most of the functions ourselves we now become team leaders and execute the test situations through other persons.

Deaf-blind children with multiple impairments often have had viral or bacterial infections involving brain tissue, optic and auditory nerves. If the infection was intra-uterine, as rubella, there are often changes in the end organs themselves. Because of the diffuse involvement of brain tissue, additional impairments show a multitude of deviant sensory and motor functions. Since many of these children are diagnosed late, that is, the dual sensory impairment is recognized after the age of 3-4

months, deprivation syndrome adds its negative influence on the total development of the child.

Rubella infants are often seriously ill for months, and they may need several surgical procedures and extended hospitalization. All these factors complicate the development of the infant and also complicate the assessment of vision and its potential use.

Children with other syndromes that include visual and auditory impairment may also have complex neurologic impairments that make the assessment of their vision difficult.

Assessment of vision is usually divided into three parts:

1. basic objective examination by the doctor,
2. observation of visual function in planned play situations,
3. training for and execution of formal test situations.

Observations during play situations are usually recorded on video film for further analysis by the team, because the child can seldom function at his optimal level when the ophthalmologist happens to visit the institution or hospital ward. In fact, these children almost never function at their optimal level during office visits. Sometimes I arrange for an appointment on a Saturday morning when the office is closed and ask the family to come with the child's favorite toys and foods some two to three hours before the examination, which is planned for the child's optimal time during the day. Since there are no other patients, I can start the examination at any time when the parents report to the receptionist that the child seems to feel comfortable. A major part of the examination often takes place in the waiting area.

During the basic examination it is often possible to get a general idea of the restrictions in the use of vision, the need for refractive correction, and to make a plan for observational situations and tests that should be used later. In making the plan there are several steps that should be considered:

1. The developmental level of the child: whether his actions are age-appropriate or

lower, and whether the profile of different developmental abilities is smooth or ragged. If the description of the child's prior level of functioning differs notably from that seen during the first examination, a reason for this should be found.

The overall cognitive level of the child helps determine the level of difficulty of the tests used. For example, in the measurement of visual acuity the child may be:  
below optotype tests (0-18 months)  
single optotypes (18-36 months)  
simple line tests (3-5 years)  
usual line tests (>5 years)

2. Communication problems are common in vision tests. They may be related to:  
visual impairment and hearing impairment  
impaired auditory and/or visual processing  
motor problems in signing or speech  
dysphasia, aphasia  
minimal seizures  
autistic, psychotic features  
short attention span  
short memory span

The level and type of communication during the tests should match the child's best mastered communication.

3. The effect of posture may be important. Therefore, the different visual functions should be observed in at least the six cardinal postures:  
lying on back  
lying on stomach upright, either sitting alone, or  
sitting supported, or  
sitting with an adult, or  
standing, supported.

An often effective, half-upright posture is holding the child in a resting position against an adult's shoulder. The changes in the child's visual functions in these different postures can be carefully recorded and reported to the special educator, so that the information can be used when planning play situations.

4. An optimal activity level should be created. Visually impaired children typically function at a low general activity level because of the

scanty visual stimulation from the environment. When auditory information is also absent the child is understimulated even more. In order to bring visual functions to an optimal level, we may need stimulation through gross motor activities, vestibular stimulation, or any other intervention that activates the child.

Hyperactive children must first calm down and relax before they can perform in the test situation. It requires both creativity and flexibility to adapt the examination to fit the optimal play situation of a hyperactive child.

5. In several eye disorders, luminance level affects the outcome of the test situation. If there is any uncertainty about the most favourable luminance level, a fair number of observations should be made at low, intermediate, and high luminance levels.
6. When we teach the members of our team about observation techniques, it is important to stress that there are several prerequisites for looking. The child must be able:
  - to be motivated
  - to attend
  - to direct gaze
  - to adjust accommodation
  - to fixate and follow a target.

One or several of these brain functions may be poorly developed. Also, because these children have a loss of function in different parts of the visual field, their fixation pattern may be confusing. The usual **central fixation** may be stable or the child may have **nystagmus**. Children with central scotomas use **extrafoveal viewing** and seem to look past, and not at the object. Autistic children may avoid fixating on objects that they know the adult would like them to look at.

The responses of these children and adults may be greatly delayed and difficult to notice. In this communication an interpreter of the deaf-blind is usually not the best person to help; the special educators and parents usually can interpret the reactions best. The response pattern of a given child becomes known over a period of time. An assessment may require

weeks or months of observation, a combination of several persons' opinions and an analysis of several hours of video films. Quite often the first impression is found to be erroneous, so we have to be prepared to accept corrections.

The persons involved in the assessment vary in different settings. Usually an ophthalmologist needs the help of an audiologist, a paediatrician (or preferably a paediatric neurologist), an optometrist (where they are available), a neuropsychologist, several special educators and of course the primary caregivers. It takes time and effort to create such a team for the careful assessment of vision, but it is the only way of gaining a reliable picture of the visual functions of multiply handicapped children.

Presently, "the assessment of functional vision" is in the hands of special educators, and it will continue to be so in the future. Since the assessment is complicated by additional neurological impairments, the team approach in the analysis of the observations will improve the quality of the functional diagnosis.

## Reporting the Findings

OUR reports are either for our colleagues on the diagnosis and medical care of the deaf-blind patient, or for the school, workplace or state and other agencies on the disability of the patient.

The diagnostic work and reporting related to our deaf-blind patients is similar to any diagnostic work when examining hearing patients. The only exceptions are the few syndromes that include both hearing and visual impairment. An exact diagnosis requires a rather thorough investigation before we can be sure whether the patient has, for example, Usher Type I or Type II. The nature of the retinal disorder is not specific enough — when assessed with the present tests — and therefore the diagnosis can



first be made after combining the results from audiological exams and balance tests with the visual data.

The reports to the schools should answer three important questions: how much vision and what kind of vision is there is for

1. teaching in group situations? Is there a need for an individual teacher?
2. mobility and orientation?
3. physical education? Is there a need for individualized P.E. planning?

Presently we have no guidelines on the visual parameters that should be used when deciding on the type of teaching — group or individual. The scanning techniques used by deaf persons vary. The capacity to compensate by using short-term memory to fuse the different pieces of visual information together varies as well. The place in the classroom and the type of visual communication also play important roles. The final analysis of functional vision for communication has to be made at the school by an experienced deaf-blind educator who can measure communication field in the classroom, knows how to observe communication in a group situation and can weigh the advantages and disadvantages of individual teaching as opposed to teaching in a small group.

The second specific question on mobility and orientation is easier to answer. Teaching in orientation should be started as early as possible in all cases of progressive field loss. There are so many things to be learned about the structure of our environment, techniques of transportation, and cues to use when vision becomes worse, that the two or three hours a week that will be available are always well spent. At the same time the teacher and the child learn to know each other and this is important for the time when mobility instruction becomes actual. It is always a sensitive issue because it immediately makes the child and the peers aware of ensuing blindness. These children seldom need the mobility techniques of the blind other than at night. Since the training occurs during the daytime many mobility teachers seem to teach night travelling by blindfolding the child. If the child sees in the dark, it would be better to use

dark enough glasses to simulate night vision. The child has to learn to combine the inadequate and often misleading visual information with the tactile information from the cane and/or sonar guide. It is then the ophthalmologist's task to specify the training goggles for training of mobility. Changes in visual field and dark adaptation should be reported to the school each time the child is seen. On the other hand the mobility instructor should report all observations made during training.

The third specific question is related to physical education. A great majority of deaf students with Usher's Syndrome report considerable difficulties playing ball games, years before they have developed absolute scotomas in midperipheral field. Since we have no clinical tests of motion perception which would depict visual functions in tasks typical to tennis, baseball or other ball games, we have to rely on information that we can get from the P.E. teacher. If the child and the teacher have contact with other older children with Usher's Syndrome they learn to observe visual symptoms and make adjustments when needed.

Children with central scotomas are rare and their situation is better understood at school because the loss of central vision can be measured by using the regular visual acuity chart. We must remember to inform the school that the child has tunnel vision whenever he uses a telescope for reading from the blackboard. The telescope for classroom work should be evaluated at school and training should be thorough. Quite often visually impaired children at the schools for the deaf do not receive the same amount of training in the use of visual aids as those children in the schools for the blind. The problems are closely the same although special attention should be given to the effect on communication. The compatibility of visual and auditory aids is a special problem to be remembered as well.

Our ability to give pertinent information on functional vision is quite limited. However, if we work in collaboration with the special educators we can be helpful in making the modifications needed in the curriculum of a

visually impaired, deaf child. Even more helpful is this collaboration in assessing the need for consultations in terms of psychological, social or vocational rehabilitation.

Our reports on adult patients should contain basically the same information as that given to the schools. Traditionally, our low vision assessments have been geared toward an analysis of vision for sustained near work, reading and writing. When examining deaf persons who use ASL we must remember that reading may not have the same role as it has in the life of a hearing person. The structure of the work needs to be analyzed with both impairments in mind.

In a previous publication (Hyvärinen 1985) I suggested that the visual functions of each visually impaired patient should be assessed in relation to orientation and mobility, ADL (activities of daily living), communication, and sustained near work. This recommendation is valid in the case of dual sensory impairment, with special emphasis on communication.

As we mentioned earlier in this chapter, our clinical assessment of vision does not give us relevant information on functional vision required in orientation and mobility tasks, ADL or communication. We can measure the communication field and thus inform about restrictions of distance, luminance, and the size of signs used. However, quite often there is an unequivocal change in the receptive skills of a deaf person without a measurable change in the visual parameters that we are used to examining. The need for more specific tests measuring perception of low contrast moving targets is obvious for the assessment of visually impaired, deaf persons.

Once we have written our reports and statements for the different offices, we should remember to ask the patient during his next visit, whether any of the suggestions on rehabilitation have been executed. Since visually impaired, hearing impaired patients do not fit the usual categories of blind or deaf, they are highly likely to be denied services that they really need. The bureaucracy of rehabilitation is often so complicated that many deaf-blind

patients give up their fight for visual aids and rehabilitation services. There are also unusual restrictions on services to housewives who take care of their children at home. They are not considered workers and are not eligible to all rehabilitation services or even assessment. As physicians we may be able to correct some of the inadequate decisions even today. Other cases of injustice require our explanation for development of sound legislation related to rehabilitation.

## How to inform about visual impairment

INFORMATION regarding any type of visual impairment is often difficult to discuss with a person who has, or is going to have, that impairment, or with the family of a visually impaired child. The main difficulty is usually related to the scanty knowledge we have about that person's history and values, his family background and their personal concept of disability. Information carelessly delivered may function like a bomb. On the other hand, if given with support, appropriate information may shorten the period of primary shock and help the person and family deal with the problem.

The most commonly expressed criticism about the medical professional relates to the manner in which a diagnosis is communicated. It might be possible to negate this criticism by saying that the traumatic experience itself causes the patient or family to have negative feelings about the person who had to relate the unpleasant news. In most cases, however, this is not true. While some of us can handle this situation without overly upsetting the families, most of us don't. A story that we hear all too often is that the diagnosis was told by a resi-



dent saying "You (or your child) have such and such a disease which causes a serious decrease in vision. Unfortunately, nothing can be done." After delivering the information, the doctor quickly disappears before the patient or parents have recovered enough to ask any questions. There are much worse scenarios, of course.

The expression "There is nothing to be done" should disappear from the vocabulary of ophthalmologists altogether. We do not deal with the situation when there is nothing to be done, that is, when the EEG recording shows a straight line. Whenever we encounter a visual rehabilitation problem, there is plenty to be done immediately and even more to be planned for the future.

A basic requirement is that this extremely important communication in the life of the patient should not be dealt with by anyone who is inexperienced in low vision services and the problems of the visually impaired. We do not allow residents to be in charge of complicated operations before they have sufficient experience with senior staff members operating. Similarly, a resident should not be responsible for communicating the news about visual impairment because he does not understand the full implications of the news. Indeed, not all staff members can handle this crucial initial communication properly. A clinician may be experienced in many fields of ophthalmology without having adequate experience in rehabilitation.

Some colleagues seem to bear feelings of guilt, much like some parents, which prevents them from having a positive approach. Any professional who does not feel comfortable about his or her contact with visually impaired patients, and in this particular case patients with dual sensory impairment, should first seek help for his or her own rehabilitation. We must learn to regard even the dual impairment as an inconvenience, a feature of the life of a particular person, and nothing more than that. We also have to understand that there is great variation in the intellectual abilities of these individuals, resulting in many different careers and lifestyles. Last, but not least, we have to

learn to understand and appreciate the small steps in the very slow development of many multi-handicapped, deaf-blind patients, and treat these patients in the same way as we treat our temporarily able-bodied patients.

The first rule of the medical profession is "non nocere", not to harm. Since we know that the information related to visual impairment is always traumatic, we must plan that situation carefully and cushion the bad news with all the support services that are available.

The diagnosis of visual impairment of a deaf or hard-of-hearing person may happen at different ages. Typically, we have to break the news of visual impairment

1. to the parents of an infant
2. to the parents of a child who does not yet understand the situation
3. to the parents of a teenager and the teenager himself
4. to a hearing impaired person.
5. to a hearing impaired elderly person

Most often the diagnosis is not quite certain after the first examination. Even if it was obvious, it is advisable to describe the situation rather briefly and arrange an additional examination as soon as possible when the person responsible for the (re)habilitation of the patient can meet with the patient or the whole family *before* the examination and be with the patient during the discussion so that he or she knows where to start when the doctor has finished. If we are going to tell the diagnosis to a deaf patient, an experienced interpreter is necessary.

The amount of information given during any appointment should be kept within the limits of coping. It is much better to answer questions than to give lectures that the patients and their families are seldom accustomed to. We should *not* plan to tell the "whole story" of the disease process with all the possible variations before the patient or the parents have some experience of living with the new facts.

### **Parents of deaf-blind infants**

A great majority of deaf-blind infants have several other health problems. The child usually



has been examined by paediatricians, audiologists, paediatric neurologists, and possibly several other professionals before coming to the ophthalmologist. When we plan the first discussion on visual impairment, it is a great help if we can include the developmental paediatrician who is in charge of the child's habilitation in the discussion. When professionals share this situation, they support each other and support the family as well by conveying the message that not even professional people are able to cope with this situation alone, but need to get help and support from others.

The parents usually remember the general atmosphere of the discussion, but not many of the details told to them. Therefore it is important that we knowingly communicate with the child with an appreciation of any functions the child may have. The developmental neurologist is usually much better than the ophthalmologist at demonstrating to the parents the strong sides of the infant. The ophthalmologist may be very helpful in explaining why some actions or reactions are not present because the visual information is not available to the infant.

In those rare cases where Usher's Syndrome is diagnosed in infancy the parents need reassuring that the child "will do well", that most children with Usher's Syndrome are above average in intelligence, very pleasant to work with, and that visual symptoms will not disturb them for several years except, perhaps, at dusk. If a child has very pronounced balance problems the parents may think that this is a sign of poor vision. It is important to clarify for the parents that balance will improve noticeably before the child is in kindergarten, and that it will not get worse later. It is not the ophthalmologist's work to inform about the contents of training programs for improved balance, but it is a good idea that you know they exist. With the diagnosis of retinitis pigmentosa, it seems to lessen the impact if the ophthalmologist stresses the importance of visual communication and creativity in finding ways to express feelings.

Parents of severely multi-handicapped infants need very special treatment. Due to the

presence of multiple health problems, the child and the parents have to see so many specialists that the number of strangers getting involved with the child actually becomes an additional impairment. To reduce the impact of this problem we can improve the situation by scheduling appointments in collaboration with other professionals and choose someone who will be primarily in charge of communication with the family; usually the paediatrician.

There is a massive amount of new knowledge that the parents have to learn during the subsequent months and years, but during the first few weeks they need and can cope with only rather basic information. The booklet "Vision in Children — Normal and Abnormal" (Hyvärinen 1988) was written for parents and other caregivers of visually impaired children to be part of this early information. Dual sensory impairment causes very specific problems which are often highly individualized and thus we have to warn the parents to read all the information with reservation and a critical mind. Many parents are likely to read medical books and to be very confused because of the conflicting information in different texts. When the knowledge of the parents increases it is easier to discuss the specific features of their child's disorder and the disabilities and abilities related to the condition. The common thread throughout all of these discussions should be to emphasize what strengths the child has, not what he has lost.

It cannot be stressed strongly enough that we should avoid the expression "blind" whenever there is even a slight possibility that the child will have some visual functions. We see so often that children behave as if they were blind during the first few months of their life, but learn to use their vision during the end of the first year, resulting in quite useful vision at the age of two to three years. Sometimes it is still possible to have a remarkable improvement in visual functions after three years of life.

The parents should be encouraged to observe their infant during different activities and at different luminance levels for any new signs of the beginning of visual functioning. The obser-

uations of the special educator during home visits are, of course, very important and should be reported regularly. As we encourage stimulation of vision, we must not overemphasize the value of visual functioning alone, since the child must learn the use of other modalities as well.

By involving the special educator in the first discussion of the visual problem we make the concept of such special services more acceptable to the parents. If the parents are told about the visual impairment and asked to contact the services themselves, it may take weeks or months before they have the courage to meet with one more professional who represents the loss that they fear the most.

### **Parents of hearing impaired children 4-9 years of age**

In this age group the diagnosis of Usher's Syndrome is the most common one. Although it would be possible to make the diagnosis during the first year of life, the suspicion of abnormal vision is usually formed when the child behaves abnormally at low luminance levels and this leads to investigations at an eye clinic.

In most cases it is impossible to obtain reliable visual fields during the first visit, so there is good reason for arranging another appointment a few days later, making sure that the parents will have ample time with the special educator of the habilitation team and with the ophthalmologist.

When we discuss a slowly progressive eye disorder like retinitis pigmentosa, it is important to remember the time scale and not to overemphasize the end stages of the disease. The often-used statement "You are going to be blind" should be carefully avoided because neither the parents nor the child will be able to understand the *present* situation if they are overwhelmed by the term "blind"\*.

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\* For those who insist that we should tell the whole "truth" at once I want to say that it does not make sense. Every one of our patients is going to die some day but we do not tell a paediatric patient that he is going to die some 50 years from now because the child does not know what 50 years means. To a five to 10 year old, anything beyond 25 years is almost beyond the grave.

If the parents ask a direct question about blindness I always state that no one can answer that question without several years of follow-up to determine the type and rate of progress of the disorder. In addition, I add that during those years we hope to be able to develop new treatments to affect the disease process itself. I know that some of my colleagues feel that this gives the families "false hope". Since I believe that the vast research in this field will lead to some clinical applications in the near future, it seems correct to let the parents share this belief. Also, when the parents learn about the joint research projects in retinitis pigmentosa they are less likely to start the exhausting and expensive hunt for a cure in less-respected places which claim to have treatment available. It also motivates them to accept the time-consuming tests we have to make for exact diagnosis.

Young deaf children are usually not at all interested in the discussion about their condition, since the vocabulary is usually way above their conceptual level. Usually I tell the child that "You know that you see just a little in dim light (if that is true). You have something in your eyes that is different from your friends' eyes but this does not bother you. We will talk about it more when you come to see me in two years." I then let the child go and play with other personnel, accompanied by the interpreter, while the parents discuss the situation with the habilitation team.

The problems related to "legal blindness" and the confusion caused by the expression "tunnel vision" are discussed in the chapter related to visual fields, and do not need to be dealt with here. I would, however, like to stress the importance of explaining the structure of the visual field in detail to the parents. In addition, I often suggest that the visual field of one eye is measured the same way as the child's visual field was measured. It is also very important to point out to the parents that visual acuity, contrast sensitivity of central vision, and color vision are all normal and that changes are usually very slow during the next ten years.

Invariably the parents want to know the ophthalmologist's opinion regarding special



education. It is actually quite common to be asked this question when a visually impaired infant is seen for the first time. Since the special education of deaf children is complicated by many different approaches, e.g. sign language versus signed English or oral communication, it is wise not to step into this trap at all but to suggest that the highly individualized needs of every child must be assessed by an experienced educator after which the proper type of school placement can be wisely chosen. If psychological tests are used in this process it is very important to stress to the school authorities that the child's placement must be based on tests suitable for testing a child with dual sensory impairment.

Since the word of the medical profession is still much respected, it may be possible to help the family get the best schooling available. Unfortunately, some states have reclassified deaf-blind children in the more general category of multi-handicapped children. As a result, deaf-blind children may not be able to have special teachers who have very specific training in deaf-blindness. In this situation, teachers who have limited or no background in teaching high-functioning children with Usher's Syndrome need very well formulated descriptions of the child's visual functions written in plain English.

Reports to the schools should stress the need for increased awareness of a child's dual sensory impairment among the teachers and other personnel as well as the students. It is quite common even today that schools for the deaf have a negative attitude in matters related to visual impairment and they often have had very little training related to the visual impairment of a given child. This child's hearing impairment is usually known to its smallest detail as are the hearing aids but knowledge related to vision is usually limited to the dioptric power of the glasses, if the child has glasses. Unfortunately, this is typical in all countries. For some unexplainable reason, the teachers for the visually impaired learn much about vision but almost nothing about hearing and teachers for the deaf learn a great deal about hearing

but almost nothing about vision, the very modality that they use in teaching.

In order to improve the quality of life of deaf, visually impaired children we need continuous awareness programs in the schools for the deaf and in all the schools where these children are integrated. We need to know that these children are harassed, even today, simply because they are different. Despite the many nice words about equal rights, our society is not yet ready to accept its disabled members; it is this disability of our society that makes these children handicapped.

### **Parents and the visually impaired deaf teenager**

The diagnosis at this age is most often Usher's Syndrome. The late diagnosis is due to a lack of knowledge regarding visual impairment in the child's environment. Typically, the school for the deaf of a given teenager does not have an early screening program for visual impairment. If the student is mainstreamed, the likelihood of missing the early diagnosis is even greater.

Before the diagnosis of RP can be discussed with the teenager and his parents, we must know how much the child knows about the function of the eye. The curriculum in science varies in different schools and many schools for the deaf have rather limited teaching in biology. Quite often we must start with basic information about the structure of the retina and the visual pathways before we can discuss RP. In order to improve the knowledge related to eyes and vision, we have included in our present project the production of three videotapes on these subjects: one for first graders, the second for third graders, and the third for fifth graders and the adult deaf population in general. Not only the deaf youngsters who have RP need to know more, but also their peers and the whole deaf community need to have a better understanding of visual problems if we want to improve the status of the deaf-blind members of that community.

When we discuss visual impairment with a teenager, the news of a progressive loss of



vision is about the last thing that a deaf teenager wants to know. The plans for a motorcycle and car become unreal, many dreams about future occupations vanish at once, and often the inexperienced family is of little help. Because the diagnosis is such a blow to the teenager and his family, we should find and diagnose these children when they first enter school, at the latest.

In the cases that we have missed, the news should be presented only after the family has met with the special teacher of the rehabilitation team and preferably has also met with a high-functioning young person with Usher's Syndrome. Since these well-adjusted youngsters are not that numerous, this is usually possible only in cities where they get their vocational or graduate schooling. It is worthwhile to develop a working relationship with these schools since the time spent in consultations is paid back when we can get the help of their deaf-blind students to prove to the teenager and his family that there is hope for the future, despite the diagnosis of RP.

Most offices that serve a large number of RP patients have one afternoon a week for just this group of patients. It is then rather easy to arrange the second visit of the new patient so that he will meet with an older, well-adjusted Usher youngster in the waiting area. Since they will share the same interpreter they will meet in the waiting area and usually will talk to each other. The interpreter who knows the older patient understands that he is supposed to greet the older patient with something such as "What exciting things have you done lately?", thus getting the patients to talk about all those things that the parents are likely to forbid as soon as they know about the visual impairment! After this type of casual exposure it is much easier to suggest to the family that they meet with other families that have gone through similar experiences.

The teenager is likely to deny the visual impairment in school for quite some time. It thus requires considerable diplomacy informing teachers and peers first about vision and visual impairment in general, and later about Usher's

Syndrome. This is especially important if there are no other children with Usher's Syndrome at that school.

### **Breaking the news to an adult hearing impaired patient**

There is a great variation of causes of vision loss in adults. The most common reasons are retinitis pigmentosa, macular degenerations, optic atrophy, hereditary or related to multiple sclerosis, choroideremia, diabetes and glaucoma. More rare causes are multiple tumors, like bilateral acoustic neurinomas combined with an additional tumor near visual pathways and causing changes in vision. Explosion accidents, severe traffic accidents, etc. may affect both modalities at once.

The only group of patients that are reasonably easy to tell about their visual impairment are the patients with either retinitis pigmentosa or choroideremia. We know that they must have had the changes for years and they know that they have been able to manage somehow despite the impaired vision. In many cases the patient is relieved to learn that he is not deviant in any other way. Deaf persons do not know much about vision in general and seldom anything about hereditary degeneration of the retina. They may have thought that all deaf persons, or all people, see like they do and that there is something wrong in their ability to observe the surroundings as carefully as other people do.

If the patient has had the hearing impairment for a long time, his work may be highly visual and he is dependent on vision in communication. The impending visual impairment will affect at least communication but it may also mean major changes in the workplace. Therefore any significant changes in vision should be discussed early in the course of the disease with a hearing impaired patient. There are now many technical solutions in most types of work to compensate for loss of vision, but the necessary skills require schooling. Since the departments of vocational rehabilitation are slow in their decisions on re-education and it also takes time to get devices, the process of rehabilita-

tion should be started before the situation at work has become disabling.

The different areas of rehabilitation — psychological, vocational, social — should be remembered. Although the professional help is important, contact with some well-adjusted deaf, visually impaired persons is usually appreciated even more. There are numerous minor everyday problems that can be solved in very many ways. Nobody knows them better than persons who have experienced loss of vision themselves.

A very common reaction among laymen and also among many professionals is that a person who is already hearing impaired and now is developing visual impairment should “have the right to retire”. For the persons with a dual sensory impairment, work may be even more important than it is to the “able-bodied” individuals. The decision to work or not to work must be carefully weighed. If the person retires, we should remember to keep an eye on the need of mental health services during this often emotionally stressful time and on the possibility of the person becoming severely isolated.

### **The hearing impaired elderly person who is losing vision**

In the older population, dual sensory impairment is common and its effects on different functions of the individual vary even more than in the younger groups. People with visual impairment may during their lives develop hearing loss, the prelingually deaf may lose vision, but the great majority of new deaf-blindness after retirement age occurs in persons with no previous experience of sensory impairment. Since these persons are so old, there is a tendency not to even consider rehabilitation or more complicated aids.

Because of limited communication, the nature of the disorder is often explained with only a few words. These older patients deserve to get exactly the same explanations as our younger patients and they may need to get the information several times, with assurance that low vision rehabilitation may help them to be independent.

Sometimes the effect of visual impairment on the receptive communication of a deaf person is not recognized, and the old deaf person is thought to be senile when he does not understand signs as well as before.

It is important to actively start teaching independent living skills, as well as communication and recreation skills to old patients since they often have amazing potential for functioning. If one has not had contact with some of the fiercely independent senior citizens, it is difficult to imagine university students in their 80s, very hard of hearing, with less than 20/200 visual acuity, living independently in the countryside, commuting daily, and preparing for their Ph.D.s.

Nowadays, “elderly” people are accustomed to an active life and may want to continue it despite the sensory impairments. Learning new techniques may take more time than for younger individuals, but basically the same skills should be taught to both groups. On the other hand, we must know that the combined sensory impairment may often lead to changes in such areas as eating habits and daily walks and become a cause of major health problems. Rather simple teaching on how to use impaired vision and hearing in ADL tasks, how to find services, etc., may improve the quality of life of these patients. It is not an ophthalmologist’s task to teach these things but it is our task to activate the rehabilitation process, and reactivate it if we notice that things are not developing as they should be.

## **PART IV**

# **Assessment of Hearing**



# Introduction

IN the assessment of hearing disorders of a deaf-blind person, or assessment of hearing in general, we have several diagnostic areas which may be grouped as follows:

1. aetiological diagnostics, for example immunological assays for rubella antibodies
2. pathological diagnostics, for example microscopic examinations of the tissues of the ear
3. topological diagnostics, for example examinations to reveal whether a hearing loss is cochlear or retrocochlear
4. clinical diagnostics, for example patient history and clinical examination because of acute middle ear infection
5. functional diagnostics to describe a hearing impairment, for example, measurement of speech discrimination in various signal-to-noise ratios
6. symptomatological diagnostics to describe patient's symptoms, for example, tinnitus, without taking the aetiology or localisation of hearing loss into consideration
7. screening tests to detect persons who may have a hearing impairment, which needs to be assessed using more precise tests.

This presentation deals primarily with functional diagnostics. Functional diagnostics are based on relations between three types of variables:

- physical properties of the sound
- physiological phenomena in the ear, the eighth nerve and the central pathways
- psychological phenomena associated with sound perception.

Based on the variables to be measured, the hearing tests may be classified into the following three groups:

1. psychoacoustic tests in which the physical properties of the sound (the stimulus) are related to the psychological phenomena associated with the perception of sound. In paediatric audiology also, the behavioral tests based on non-conscious reactions of the child are grouped in this category

2. acoustic tests, like measurement of the middle ear acoustic impedance. Only measurement of the static impedance of the ear should be regarded as purely acoustic measurement. In practice, for example, the recordings of middle ear muscle reflexes are included in this group. Since the measurements are usually performed by means of electroacoustical devices, this category is often referred to as the electroacoustical measurement
3. physiological methods like measurement of the evoked responses at various levels of the auditory pathways. Attempts to employ other physiological responses like respiratory and circulatory reactions have also been made.

The acoustic and physiological measurements are often called electrophysiological or objective measurements.

The tests of equilibrium, often called vestibular tests, do not belong to hearing assessment, yet, at least in Scandinavian countries, are often performed in the departments of otolaryngology. Vestibular disorders are anatomically intimately related to lesions in the inner ear or the eighth nerve and play a significant role in the (re)habilitation of deaf and especially deaf-blind persons. Therefore tests of equilibrium are an essential part of the examination of a deaf-blind person.

In the assessment of impaired hearing we:

1. measure the degree of hearing loss and measure hearing thresholds
2. determine the type of the hearing loss: conductive, sensorineural or combined, and localise the sensorineural hearing loss, be it cochlear, retrocochlear or central. Possible recruitment associated with hearing loss is taken into account in the habilitative or rehabilitative measures; possible adaptation may also have its implications on further procedures.

The audiometric tests also contribute to the diagnosis of the disease. The degree and type of hearing impairment form the basis when the chances for therapeutic, habilitative or rehabilitative measures are assessed.

In this presentation the following subjects are briefly dealt with:

1. communication during test situation
2. pure tone audiometry
3. speech audiometry
4. impedance measurements
5. recording of auditory evoked potentials
6. paediatric tests
7. behavioural observation
8. fitting of hearing aids and other technical devices
9. vestibular tests
10. how to inform about hearing impairment.

## Communication during test situation

THE problems of communication in medical examinations and the role of the interpreter are discussed in depth in parts I and II of this book. Everything stated in those two parts is applicable to the assessment of hearing as well. However, there are some additional details which the otolaryngologist or audiologist should be aware of when performing a clinical examination.

Otolaryngologists and audiologists are likely to be disturbed by abnormal eye contact with a deaf-blind patient, because they are seldom familiar with the nature of the visual difficulty, for example, the need for extrafoveal fixation. Although they, by their profession, should be familiar with the techniques and strategies of interpreted conversation, I would like to emphasize that the doctor should focus his attention on the patient and not the interpreter.

The interpreters are usually aware of, for example, the tunnel vision of the patient and how it affects interpreting. However, it is also the doctor's responsibility to check that the

patient can receive the signed (and spoken) information.

The illumination preferred by many otolaryngologists is too dim for communication in sign language, especially with deaf-blind persons.

The white clothes worn by doctors may blur the vision of some deaf-blind patients, especially those with Usher's Syndrome. The frontal lamp or mirror used as the examination light may be especially detrimental to visual communication. Since the light is coaxial with the visual axis of the doctor, he can easily dazzle the interpreter or the patient during the examination or conversation. In the case of Usher's Syndrome this may dazzle the deaf-blind patient for a long period.

In case the doctor is not familiar with the communicative capacity of the patient or if the communication has deteriorated recently, due to loss of hearing aid, change in central vision etc., it is important to routinely check that the messages have not been misunderstood. At the beginning of the conversation, this may be necessary after every sentence.

Printed questionnaires may be used to obtain some features of the patient history. Answers to standard questions and old documents can never replace face-to-face patient history. Therefore, sufficient time should be reserved for review of the documents and for discussion with the patient.

Every contact of a patient with a doctor has its influence on, and is a part of, rehabilitation or habilitation. This has to be taken into account especially with patients who have the double handicap of deaf-blindness, in which both of the two distance senses, vision and hearing, are impaired or lost. The patient's capacity for communication is reduced and may be further affected temporarily by the worries caused by deterioration of sight and/or hearing. Also, the doctor must be aware of the positive or negative effects of his own behavior. In addition, the doctor needs to be tolerant to the sometimes odd and harsh-appearing behaviors of the deaf and deaf-blind patients.

If the interpreter is not familiar with the

otolaryngological and/or audiological examination, the procedures and instruments should be explained to him beforehand. During the examinations and tests, sufficient time has to be reserved for the interpreter to explain the next procedure to the patient. If possible, it is advisable to rehearse various examinations and tests with the interpreter step-by-step before examining the patient.

The otolaryngologists quite often perform small operations in their offices. They should be prepared in case the interpreter or the patient faints.

Interpreting in the operating theatre during operations performed under local anaesthesia may be problematic. The interpreter must be taught to follow the rules of sterility. Often the eyes of the patient are covered which requires changes in interpreting. The real need for covering the patient's eyes must be considered carefully in each individual case. When tactile interpreting is necessary then the sequences of the operation have to be described carefully beforehand, as do possible complications. If an operation is performed under general anaesthesia it is worthwhile to have the interpreter available in the recovery room.

Every person taking care of the examinations, tests and procedures of a deaf-blind person should be aware of the responsibility of the personnel to ensure that communication with the patient is arranged in a reliable way. During various steps of the examinations and interventions it has to be confirmed that information is correctly conveyed to the patient. Communication is co-operation between the otolaryngologist, the audiologist, the patient and the interpreter.

## Pure tone audiometry

PURE tone audiometry, whenever applicable, is the basic test in audiological examinations.

Usually, it is performed by means of earphones. The free field measurements are not discussed in this connection.

Generally, pure tone audiometry includes measurement of hearing thresholds by air induction (AC) with octave intervals at frequencies from 0.125 kHz (0.25, sometimes 0.5 kHz) to 8 kHz plus at some of the intermediate frequencies, usually 3 and 6 kHz (sometimes even 1.5 and 0.75 kHz). In bone conduction (BC) measurements, usually only frequencies from 0.5 to 5 kHz are measured. In BC measurements the ear, which is not tested, has to be masked; masking noise is used also in the AC measurements, in most cases with pathological hearing thresholds.

Even when performing this rather simple test on deaf-blind persons, more time than usual is needed, which should be taken into account when the appointments are made. Before conducting the test, the audiometer, the headphones, the response tangent and the test situation are demonstrated to the patient and the interpreter. Sinus tones used as signals are unnatural and the subjects should become accustomed to them before the testing. Between sequences of testing the interpreter can convey spoken instructions in sign language.

Often, especially when children are examined, it may be advisable not to use the response tangent to indicate that a test sound is heard. Instead, it may be easier for the patient to raise the hand on the side where the signal was heard. This may be especially worthwhile since this will help to distinguish between reactions to the signal itself and to the possible confusion caused by the masking noise.

When examining children, and other difficult-to-examine patients, it is rather common that masking noise cannot be used at all. In those cases, the results of the BC measurements represent only the better ear. The same holds true also for the AC thresholds in case of an asymmetric loss.

Children and the profoundly deaf require much time to practise the test before reliable results are obtained. The less actively the patient uses his or her hearing, the less valid



are the first results. It is not exceptional that the test has to be repeated in several sessions before the results become reliable.

## Speech Audiometry

THIS paragraph is focused mainly on speech audiometry performed with earphones. To some extent, the free field measurements will be dealt with in subsequent paragraphs on pediatric tests and hearing aid fitting.

The speech signal, in contrast to the sinus sounds, is more meaningful to patients, including children, who have useful hearing.

Test word lists are phonetically balanced. In many languages, however, the number of word lists suitable for younger age groups is rather limited, insufficient or missing. We should use word lists suitable for the developmental and not the calendar age of the patient. If the vocabulary of the patient is very limited it might be advisable to use a live voice test with the vocabulary of the patient.

When testing deaf-blind patients no special techniques are needed. Conventional speech audiometry reveals speech reception threshold and discrimination at the optimal hearing level and gives quite a good idea of the social hearing of the patient. However, additional tests are needed. Marked roll-over (deterioration of discrimination with increased stimulus intensity) indicates difficulties in everyday listening situations. In addition to the conventional tests, standardized speech audiometric tests in different, especially negative, signal-to-noise ratios are needed to depict the patients' difficulties in everyday life.

In speech audiometric tests, like in pure tone audiometry, the interpreter describes the test situation, but is not involved in the test itself.

## Impedance Measurements

THE impedance measurements belong to the electrophysiological, the s.c. objective measurements. They do not require active participation of the subject. In clinical practice, the purpose of these tests may be listed as follows:

1. assessment of middle ear function: middle ear pressure, possible presence of middle ear effusion and condition of the ossicular chain
2. assessment of the reflex arch of the middle ear muscle reflexes (the stapedius and the tensor tympani reflexes). In practice, the stapedius reflex is more often employed; the reflex arch of it includes the middle ear mechanism of the afferent side, the inner ear, the eighth nerve, the brain stem, the seventh nerve and the middle ear mechanism on the efferent side. Registration of the tactile stapedius reflex as well as the tensor tympani reflex are used relatively seldom in clinical practice. Registration of the middle ear reflexes to assess the reflex arch has the value of a screening test done before more sophisticated and specific tests
3. the stapedius reflex thresholds are often used as a measure of recruitment; in that purpose, the pure tone hearing thresholds have to be known. Especially in paediatric audiology, the stapedius reflex thresholds are valuable when assessing recruitment and its implications for the fitting of the hearing aid
4. use of stapedius reflex measurements to assess actual hearing thresholds has been abandoned due to considerable inaccuracies of the results.

During impedance measurements, no active participation of the patient is required. Since these tests give versatile information they should be used in assessment of every patient with limited communication.

Some sequences of the impedance measurements may be somewhat unpleasant: the tightness of the ear probe in the ear canal, the sensation of changing air pressure in the ear

canal during tympanometry and loud signal sounds when the stapedius reflexes are registered. In spite of abnormal hearing thresholds, signals at high energy levels may be extremely unpleasant in an ear with pronounced recruitment. Therefore, the different sequences of the measurement are explained meticulously and maybe some even rehearsed before actual measurements. This is important for two reasons. Firstly, the patient should not move during the test and this is achieved if the patient knows what is to be expected. Secondly, the impedance measurements may be the few successful ones in assessment of the difficult-to-examine patients.

The interpreter can be of great help during impedance measurements. The course of the measurements is explained thoroughly to the patient before the measurements, and supportive, repetitive communication between the actual measurements is helpful.

## Auditory evoked potentials

REGISTRATIONS of auditory evoked potentials belong to the objective and electrophysiological tests. The term "audiometry" should be avoided in this connection, since these examinations do not measure actual hearing, but register auditory evoked potentials, electrophysiological events in the hearing pathways.

Various types of potentials at various levels of the hearing pathways can be recorded. To these belong the potentials from the cochlea and the first neuron (electrocochleography); the potentials from the acoustic nerve and the brain stem (acoustic brainstem responses) and those from the cortex (cortical evoked potentials) etc.

The potentials employed most often in clinical practice are those from the acoustic nerve

and the brain stem. Several terms are used to depict these measurements: auditory brain stem responses (ABR), brain stem electric/evoked responses (BSER) and brain stem auditory evoked potentials (BAEP). The name "audiometry" is not valid, thus the terms "brain stem audiometry" (BRA) and "brain stem evoked/electric response audiometry" (BERA) should be abandoned. In this presentation, the term auditory brain stem responses (ABR) is used. The following lines on auditory evoked potentials are focused on ABR.

The stimuli used in the ABR are most often clicks. Filtered clicks and tone bursts may also be used, especially if the measurements are done to confirm hearing thresholds. The measurements can be performed in a waking state, during natural or induced sleep, in sedation or under general anaesthesia. Usually, and preferably, the recordings are done in a Faraday's cage, but with modern equipment this is not necessary and the test can be done in an operating theatre in connection with therapeutic interventions.

The purposes of employing the ABR in deaf-blind patients could be listed as follows:

1. By means of the ABR, valuable information regarding the lower parts of the hearing pathways can be obtained for neurological diagnostics.
2. The ABR can be employed to confirm the hearing thresholds obtained by other tests. This is especially valuable in the case of small children and other difficult-to-test patients. In these cases, the ABR is an essential part of the test battery. Anyway, the ABR never replaces the other tests but supplements them. There are two important points to be stated. Firstly, the ABR depicts the hearing pathways only to the level of the brain stem and reveals nothing about the psychological phenomena associated with sound perception. Secondly, and especially, if clicks are used as stimuli (which otherwise would be preferable), the result is related only to the thresholds at the higher frequencies.
3. The ABR can be used in the purely neurological examinations of deaf-blind patients.

Since the ABR, like registration of other auditory evoked potentials, belongs to the s.c. objective measurements, the patient is not required to actively participate. Also, there are no unpleasant experiences during the test.

In clinical practice, the use of electro-cochleography (ECoG) and cortical responses (CERA, ERA-late etc.) has often been abandoned. Registration of the so-called 40 Hz response may, in time, partly replace the ABR, especially in paediatric practice. Everything stated regarding the test situation of the ABR is applicable to the registration of the 40 Hz response as well.

In the registration of auditory evoked potentials, the role of the interpreter is very much the same as in the impedance measurements. Although the ABR is not painful or otherwise unpleasant, the interpreter is needed to explain the procedure to the patient. The ABR is a non-invasive test and thus causes no ethical questions, however if sedation or general anaesthesia are going to be used, the aim of the test and the medication have to be explained to the patient or to his parents/guardian and the consent has to be obtained.

## Paediatric Tests

IF a child is suspected of having a hearing impairment, his hearing must be assessed as soon as possible. This is even more important if the child is, or is suspected to be, deaf-blind. Sight and hearing are the two distant senses which are both necessary for the child's normal early development. Hearing is needed for the normal communicative development of the infant. It is often stated that an infant's hearing should be assessed and the habilitation started before the age of one year. The preferred early diagnosis and habilitation, however, has no lower limit and the upper limit should be set at an earlier age of nine, maybe even six months.

In addition to the formal auditory tests, much of the information regarding a child's hearing is obtained by non-formal observation of the child (see next paragraph). The most useful tests vary at different ages and each test must be suited to the child's developmental age, rather than his calendar age. In the following few lines, only the tests used most often in everyday practice are dealt with. The screening tests are not described in this connection.

Observation audiometry is used primarily at the developmental age of 0.5 to 1.5 (2.5) years. The signal is preferably a warble tone or a filtered environmental sound with the centre frequency at the respective frequency to be tested. A sinus tone is often less interesting as the signal for a young child.

During observation audiometry of a deaf-blind child, the interpretation of the child's reactions is often difficult. Especially, the child's orientation to the signal is rather poor. It might be advisable to have two observers present when testing a deaf-blind child, even more so if the child has any additional handicaps. Videorecording of the entire test situation is often of value. Obviously, the visual reinforced audiometry (VRA) is seldom suitable for deaf-blind paediatric patients. Acoustically measured toys may be used in hearing assessment. The child's play or his reactions to the sounds from these playthings can be employed in the analysis.

An infant may accept the use of earphones from the age of two years. At the beginning the examination is performed as play audiometry — "The sound is coming from the toy, which you put away once a sound has appeared; the next sound will come from another toy etc.". The use of earphones is to be preferred as soon as possible due to various sources of imprecision in free field examination. On the other hand, there are appreciable difficulties in interpreting the play situation to a deaf child, and even more so to a deaf-blind infant.

In speech audiometric tests, the vocabulary and the developmental age of the child have to be taken into account. Obviously, more variable word lists are needed than are available in



everyday clinical practice. In the case of young infants, the test should preferably be presented in the form of simple questions or tasks, "Show . . .", "Where is . . . ?" etc., instead of separate words to be repeated. Loss of sight naturally causes many inconveniences in this form of the test, and much improvisation is often needed.

Since it is not unusual that word lists for each child are not available, the examiner must be prepared to use live voice tests as well.

The errors made by the child during the speech audiometric tests should be meticulously recorded. These records give valuable information on the child's vocabulary. Furthermore, these records may also indicate the kind of discrimination disturbance the child has.

The impedance measurements and the ABR belong almost inevitably to the test battery of each hard-of-hearing, deaf or deaf-blind child. For those examinations see the respective paragraphs.

The few tests described in this paragraph are not meant to give a comprehensive picture of paediatric audiometry. Many clinics use some additional tests which they are accustomed to. Plenty of valuable information is also obtained through non-formal testing. Several methods have to be used in a parallel way, and repeated examinations are needed before an infant's hearing can be assessed with acceptable accuracy. The lower the child's developmental age and the worse his hearing, the more cumbersome are the examinations.

The interpreter's role in paediatric audiologic examinations is extremely difficult. Often there is no common communication yet, and improvisation is the only way to solve the problem. The messages should be conveyed as concretely and simply as possible, however, the attention of the child should not be distracted from the test itself.

## Behavioural Observations

THIS paragraph can be expressed in one sentence: anything we know of a person, his history or behavior yields valuable information about his hearing.

Non-formal testing is especially needed if the patient is an infant, at a low developmental level, not co-operative or multi-handicapped. This implies that non-formal information is an essential part of the examination of deaf-blind children.

In the case of children, anything expressed by the parents must be appreciated. Their suspicion of a child's hearing loss is always to be respected. Their remarks on the child's behaviour in various situations often gives important clues about the patient's hearing. Similarly, observation of the patient's behaviour during the clinical examination is an essential part of the hearing investigation. Among other issues, the mode of communication as well as the distance of comfortable communication provides information about the patient's hearing. His language, his vocabulary, any faults in intonation, phonemes etc., should also be observed during the examination.

Paediatric patients quite often need hospitalization for their hearing tests and other observations. Every aspect of the hospital situation, from the wards and especially formal play situations, must be exploited for the evaluation of the hearing and communicative skills of the child. Thus, everyone belonging to the hospital personnel belongs also to the team examining the child's hearing. This holds true also for the interpreters.

Hearing assessment of a child or of a patient at a low developmental level often requires several parallel and repeated examinations. Furthermore, follow-up of a patient is also part of the assessment, especially in the case of difficult-to-test patients. It is not unusual that our view of the hearing of such a patient

changes or even becomes totally altered during the follow-up.

In addition to the uncertainty of the test results, the possible progression of the hearing loss also requires repeated examination. If the child has a double handicap, deaf-blindness, or even more importantly, if he or she is multi-handicapped, frequent retesting is needed. Firstly, the results of the hearing tests in these children are often imprecise. Secondly, in the case of a double or multiple handicap even a slight progression of the hearing loss often necessitates rapid new interventions. Once the hearing thresholds have been ascertained and the hearing loss has been proven to be non-progressive, the frequency of the retests may be diminished.

## Fitting of hearing aids and other technical devices

DEAF-BLIND persons can often use many of the technical devices aimed primarily at deaf or hard-of-hearing patients. In a majority of these, for example, in many signal or alarm indicating devices, the signal can be changed from a visual to a tactile one. Always, when fitting technical devices to a deaf-blind person, the needs and capacities of the particular patient must be carefully analyzed and taken into account. Today, the technology provides sophisticated tailor-made solutions to fit the requirements of each patient.

Only some features of hearing aid fitting are discussed here. Most of the deaf-blind persons, like other hearing handicapped, benefit from hearing aids. This holds true even with very

profound hearing losses with, for example, actually no word discrimination. These patients will, by means of amplification, have the chance of perceiving environmental sounds as well as some prosodic features of speech communication. Both of these features are very valuable, especially for deaf-blind persons.

The cause of avoidance of hearing aids by profoundly deaf or deaf-blind persons is often simply the delay of hearing aid fitting. If a person with a profound hearing loss gets acquainted with the acoustic environment at a late stage of his development, it is often very difficult to learn the value of auditive signals and thus something crucially important in his habilitation is lost forever. Some patients are even afraid of wearing hearing aids, as this might be taken as a sign of being capable of speech communication.

When choosing hearing aids for deaf-blind persons the general rules of fitting are valid, of course. Binaural fitting is preferable to enable as good orientation within the sound field as possible. In the case of deaf patients, and especially of the deaf-blind, prescriptive methods are to be preferred. To ensure correct fitting, insertion gain measurements are highly valuable. This does not mean that free field measurements of the functional gain or subjective judgement of the patient should be abandoned. On the contrary, they have to be taken into account, but the hearing aids must also be objectively satisfactory, especially in the case of these patients. This is most reliably achieved by means of insertion gain measurements.

Deaf persons, and deaf-blind persons especially, need plenty of time to get used to hearing aids. The importance of efficient counselling is evident. The patient must be carefully followed-up and their use of hearing aids encouraged.

The interpreter is needed all the way through the hearing aid fitting process, from the audiometric tests to the counselling visits. The advantages of hearing aids and other technical devices have to be carefully explained to the interpreter to avoid the subconscious negative attitudes that even some of the interpreters might have.

The hearing aids are definitely not in competition with the interpreters! Likewise, the medical and rehabilitative personnel may sometimes feel that no amplification is needed or beneficial in the case of profoundly deaf deaf-blind persons.

In the future, cochlear implants may play an important role in the rehabilitation of at least some of the deaf-blind persons.

## Vestibular Tests

VESTIBULAR and other equilibrometric tests should be included in the examination of a deaf-blind patient. Firstly, peripheral or central vestibular disorders are not infrequently associated with the diseases causing the hearing losses. Secondly, any disorder in the vestibular function complicates the mobility problems and training in a deaf-blind patient and must therefore be taken into account in habilitation or rehabilitation.

Vestibular tests are often very difficult to perform on a deaf-blind patient due to loss of fixation, sight etc. The difficulties will be encountered already at the beginning of the electro-oculographic (EOG) tests. The difficulties are pronounced while performing the calibration, any possible central ocular tests, as well as nystagmographic recordings.

Before the EOG, the clinical otoneurological examination has to be performed. Meticulous history-taking is of utmost importance, especially in these patients. Whether and which other specific tests belong in the examination depends on the case history and clinical findings, and is also a matter of the policy of each department.

In addition to the technical problems, the vestibular tests are also rather problematical with regard to interpreting. The patient often feels the vestibular tests especially irrelevant, and furthermore, some of them, like the caloric tests, may be somewhat unpleasant. All of this causes a considerable need for careful

explaining and interpreting of the test situation to the patient.

Another practical difficulty of these tests is that considerable parts of them are performed in the dark and/or with eyes closed. Therefore the test situations have to be rehearsed beforehand. Sufficient time has also to be reserved afterwards for discussing the tests.

Due to technical problems, the recordings of the tests will almost inevitably include many artefacts and may be very difficult to analyze, therefore repeated tests may be needed. The motivation of the patient for new test sessions depends very much on the co-operation of the personnel and the interpreter, during the first visit.

## How to inform about the hearing impairment

THE reader is referred to the two paragraphs in Part III of this book, "Reporting the findings" and "How to inform about visual impairment". The former of these paragraphs deals with reporting the findings to the professionals and the latter to the patients or their parents. Yet, there are some words to be added, repeated or rephrased. In this paragraph, reporting to the patients themselves, their parents or guardians only will be discussed.

The first thing to be aware of is to be honest. Once you have been found to have lied, anything you say later will be suspected to be another untruth. This holds true also, and especially, with the children. However, being honest does not mean to be rude.

When telling somebody that he/she or their



child has a hearing loss, one has to be very considerate, even more so in the case of the double handicap, deaf-blindness. One has also to remember that if the message is to be interpreted, the tactfulness is the task of the doctor, not of the interpreter.

The attitude of the doctor must always be positive, not hopeless or pitying. The starting point must be that something can and will be done. One of the tasks of everyone belonging to the personnel is to show that they are there to support and help the patient and the family.

When explaining the hearing (or possible vestibular) impairment and its consequences, the person explaining must be experienced with the subject. If, however, and this will happen often enough, something cannot be answered, the only correct policy is to humbly confess the fact and that, if possible, the answer will be found.

When the patients or their parents are informed about the hearing impairment and its consequences, the information must be conveyed as simply as possible. The interpretation will also necessitate this. Complicated medical terms must be avoided; especially those coming from foreign languages, Latin and Greek mostly. As always when communicating

with other people, the professionals should remember that it is best to use the simplest language.

It is not wise to try to present all of your knowledge in one session. The patients and their parents cannot tolerate very much, especially at the beginning. The amount of information they can perceive and accept will grow step by step and this has to be acknowledged by the professionals. The professionals have also to accept the fact that much of the information has to be repeated several times. The more often something is said, the more it is prone to be denied by the patients or the parents.

When talking about the prognosis, and the future in general, one has to be especially delicate. The attitude must always be positive but unrealistic expectations must not be given.

Optimally the habilitation or rehabilitation should be run by one team, or at least be coordinated by one person or a relatively small team. Thus, the information received by the patients should be "filtered" to be concordant. Divergent statements and opinions, as well as different terms and phrases, can be explained to the patients or to the parents and much confusion can be avoided.

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- A complete bibliography on deaf-blindness is available at the Nordic Staff Training Centre for Deaf-Blind Services, Slotsgade 8, DK-9330 Dronninglund, Denmark.
- The following unpublished papers might be found interesting. They are available from Theresa Smith, 8024 Bagley Avenue North, Seattle, WA 98103.
- Pinder, G and Motulsky, A, Interpreting for Deaf-Blind People.
- Smith T, Should I Take This Assignment?
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